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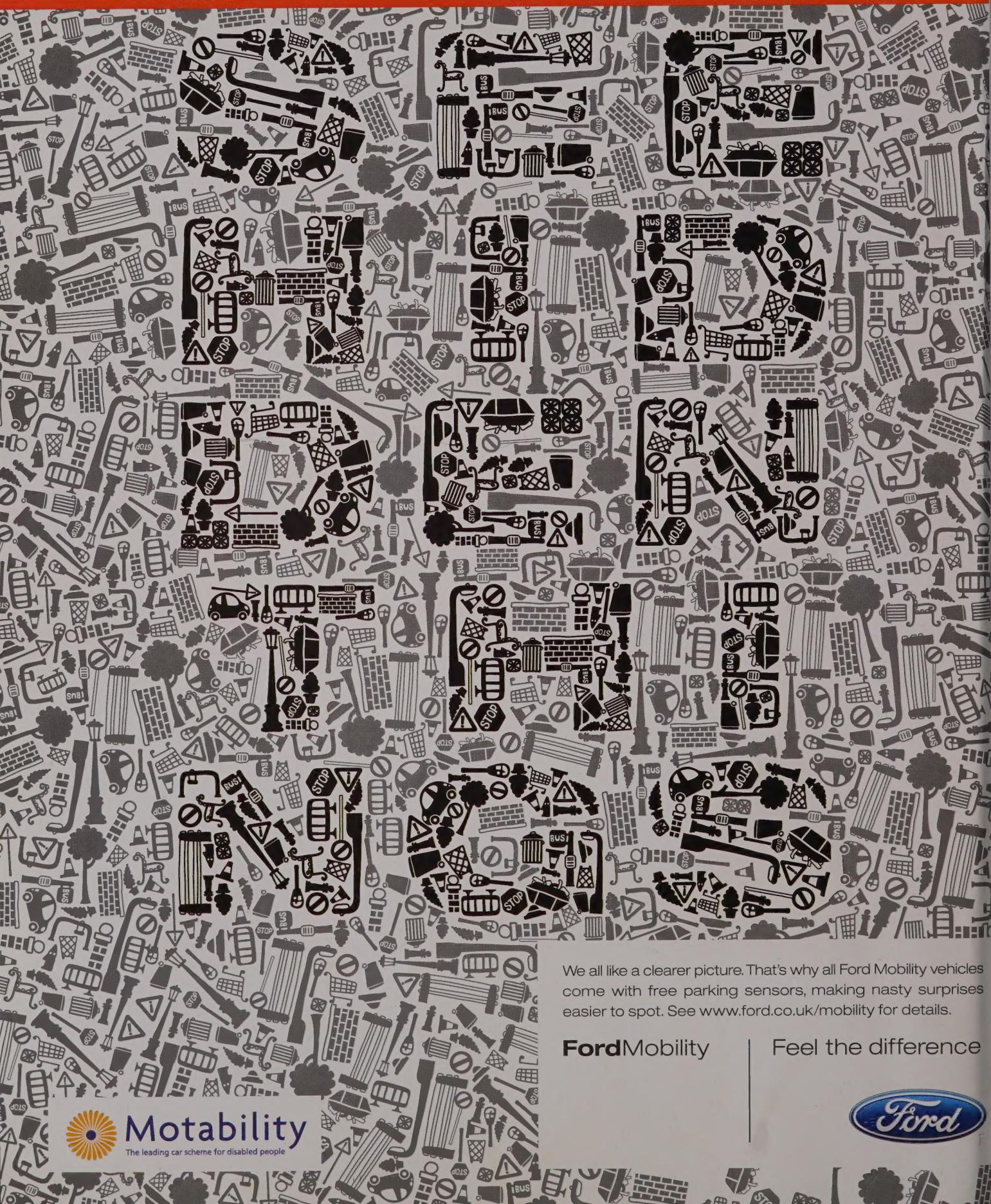
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# editorial

## Electing for reform

It's been interesting to note the fuss that occurred over the fact that "hundreds of people" were unable to cast their vote in some constituencies in the general election.

While this certainly raises issues about the robustness of an electoral system which partially breaks under the less than enormous pressure of a turnout of 65 per cent, it also caused some of us to raise a wry smile.

Those who turned out to vote at the last minute would have found little sympathy from those disabled people who were either unable to vote at all or encountered a degree of hassle in our attempts to exercise our democratic right.

How ironic, for instance is this? As a visually impaired voter, in order that my wife could facilitate me with the completely inaccessible electoral process, we were also required to complete a form, in print and therefore equally inaccessible.

Meanwhile there were other disabled would-be voters who would regard my situation as relatively minor. Physical barriers would have

prevented some people from even getting into polling stations which were sited in premises simply not accessible. Others encountered a system which in and of itself was just not accessible to them for reasons different from my own.

**We're not just talking about different systems for voting and calculating the result**

Since the election, there's been much talk of electoral reform. To that, we disabled and disenfranchised people say, "bring it on". But we're not just talking about different systems for voting and calculating the result.

Britain needs an electoral system which is accessible to all. One which doesn't leave people wondering whether they should make the effort of going along to a polling station which they may not be able to get into once they get there. A system which would allow each of us to cast our votes independently and on equal terms.

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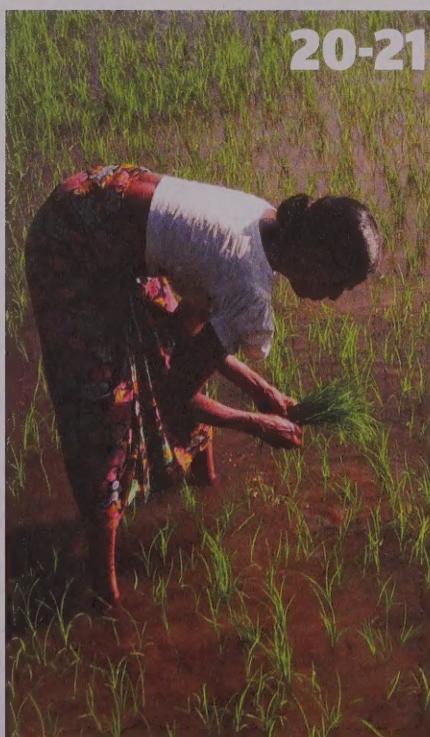
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# newsview

## Alliance central for Hawkes' Scope vision

Three months after his appointment, Richard Hawkes (pictured, right), Chief Executive of Scope (the charity that publishes *Disability Now*) has spoken about the organisation's relationships with disabled people, its role as a charity and the need for it to be more confident and outward facing.

"Everything I'd heard made me aware that Scope had once been one of the strongest organisations in the country," he said.

But, he goes on, the organisation has to examine where it came from.

"We, as a large influential charity, built up our power in ways that weren't perhaps the most appropriate recognition of the rights of disabled people."

And he's now convinced that it's time for Scope to put disabled people at the heart of everything it does.

"It's about ensuring that disabled people are part of every decision we make, and that we're striving to be, as an organisation, how we'd like society to be.

"I also think that being an ally of disabled people means being an ally of disabled people's organisations (DPOs). And that means recognising the position we occupy, the



power we have, and using it appropriately, working in partnership with DPOs and involving them closely in any external work we do."

As we speak, Hawkes is just back from two days spent with the partners in Disability Lib, the big lottery-funded coalition, hosted by Scope, which exists to build up strength and capacity in disabled people's groups.

But he seems now to be talking of a much broader, more organic alliance.

There have, however, been tensions in the past when groups of disabled people who provide services and, in particular, training, have found themselves competing with and losing

out to Scope in competition for contracts.

So does Hawkes think that in view of power imbalances, Scope should give way in those circumstances?

"There are some areas which would seem the natural preserve of disabled people.

"One example would be disability equality training. That should only ever be delivered by disabled people, and the organisations that run it should be DPOs.

"I think there are lots of areas where we have to step back and question how we got our power and legitimacy in the first place."

He also recognises the potential tensions that can

exist between charities and their disabled constituencies.

"There is a tension between portraying ourselves as a charity and trying to be an ally of disabled people because being an ally isn't about charity and being charitable.

"But I'd question whether or not Scope needs to present a nice cuddly charitable image of itself.

"I think we can be a lot braver about the issues on which we can talk. So if there are issues that are important to disabled people, Scope should be out there seeking to ensure that voices can be heard and that disabled people's opinions can be heard."

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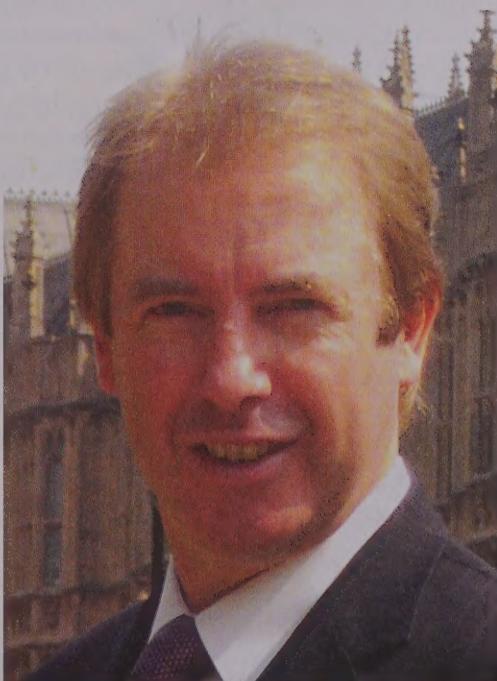
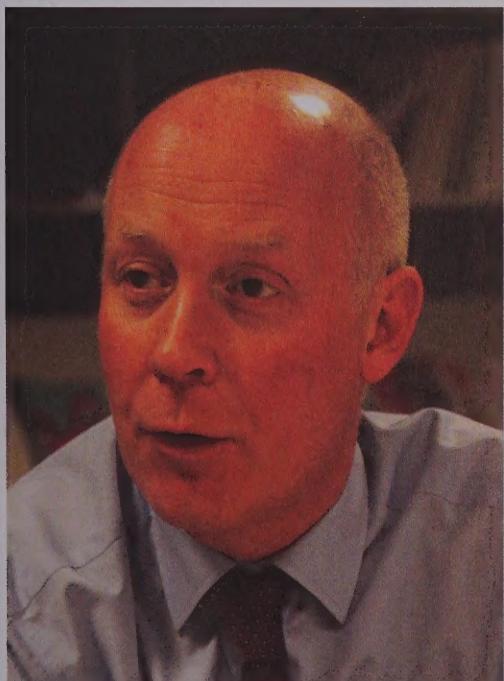
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# newsupdate

## Allies lost in Westminster election shake-up



**Missing in action:** Top left, Roger Berry (Kingswood). Top right, Jonathan Shaw (Chatham and Aylesford). Bottom left, Phil Hope (Corby). Bottom right, John Barrett (Edinburgh West)

### Sunil Peck

Three Labour MPs regarded as important allies of the disability movement have lost their seats in the Commons as a result of the slump in Labour's vote in the 2010 general election.

The chief loss is felt by the ousting of Roger Berry, who co-chaired the All Party Parliamentary Disability Group with Baroness (Jane) Campbell.

Berry lost the seat of Kingswood, which he had held since 1992. It was won by the Conservatives, on a swing of nearly ten per cent.

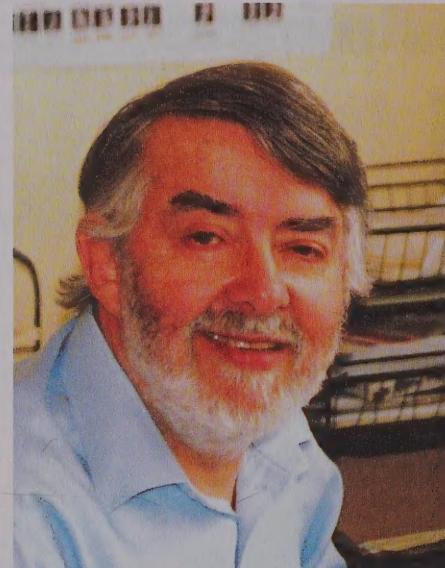
A frequent critic of his own Government's failure to extend winter fuel payments to disabled people under the age of 60, Berry has received plaudits from activists, campaigners and fellow parliamentarians for the work he did to promote independent living and lift disabled people out of poverty.

Anne Begg, the disabled MP for Aberdeen South since 1997, paid tribute to Roger Berry and said that he had earned a great deal of trust in Parliament and had been an "absolute champion for the rights of disabled people".

She added: "Roger did indeed vote against the



# newsupdate



**The survivors:** Left, David Blunkett (Sheffield Brightside). Centre, Paul Flynn (Newport West). Right, Anne McGuire (Stirling).

Government but he wasn't a serial rebel. So he had respect from the Government side and from the backbench side, so he was able to get things changed. He worked tirelessly and very hard for disabled people and I think he will be a huge loss in the House of Commons."

A second MP, Jonathan Shaw, appointed Minister for Disabled People in October 2008, was defeated by the Conservatives after a swing of more than 11 per cent in Chatham and Aylesford.

He had held the seat since 1997 and was also Minister for the South East.

A staunch defender of Labour's controversial policies to support more disabled people into employment, he presided

over the ratification of the United Nations convention promoting human rights for disabled people, and was responsible for overseeing the progression of the Equality Act.

The third MP to be ousted was Phil Hope, the care services minister and Minister for the East Midlands. Hope lost Corby where he had been the MP since 1997.

As one of the key figures involved in drawing up Labour's plans for a national care service, Hope will be associated with the fears that arose over the future of Disability Living Allowance when Labour first published its social care green paper.

He was one of the MPs tainted by the expenses scandal and in 2009 agreed

to return more than £40,000 that he had claimed on his second home.

In addition, John Barrett, who had been the disability spokesman for the Liberal Democrats since 2008, retired from his seat in Edinburgh West. The LibDems held the seat but with a reduced majority.

Meanwhile, Paul Maynard will enter the Commons as part of the new intake of MPs after winning the seat of Blackpool North and Cleveleys for the Conservatives.

The seat had been held by Labour since 1997 but Maynard triumphed with a majority of more than 2,000.

He told *Disability Now* (see page 14) he was thrilled to have the chance to serve as an MP and said: "I think I've demonstrated

that having a disability should be no bar to getting elected, especially having a disability like cerebral palsy (CP) where people might not understand what it is and might think that you're learning disabled."

He will join three Labour MPs: David Blunkett, who was re-elected in Sheffield Brightside with a majority of more than 13,600 in the seat he has held since 1987; Paul Flynn who was re-elected in Newport West with a majority of more than 3,500 and who has advocated the use of medicinal cannabis to ease the pain caused by conditions like multiple sclerosis; and the well-respected former Minister for Disabled People, Anne McGuire, who increased her majority in Stirling.



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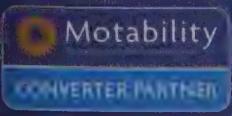


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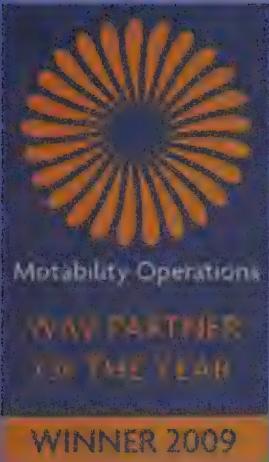


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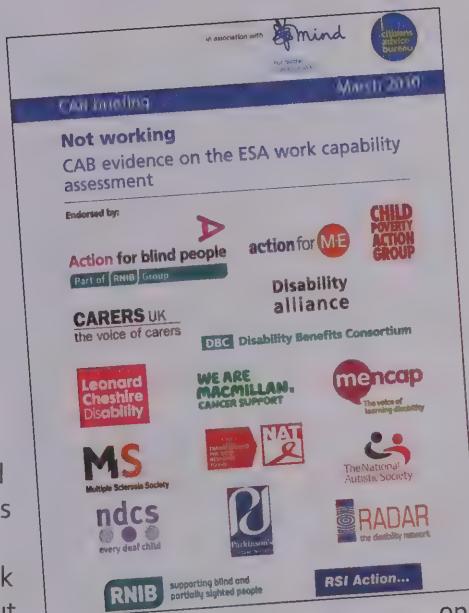
## Work assessment isn't working



Recent research by the Citizens Advice Bureau has provided evidence of what **Ruth Patrick** and others always feared: the new Work Capability Assessment (WCA) which determines people's eligibility for Employment Support Allowance (ESA) is not fit for purpose

**T**his is how ESA works. New claimants undergo a medical (the WCA) to determine whether or not they are able to participate in paid work. On the basis of the medical's results, individuals are placed in one of three groups. Many will be found able to work, refused ESA, and instead given Job Seeker's Allowance. Others found capable of some paid work will receive ESA and be put in an employment-group, where they are expected to participate in work-related activity as a condition of benefit receipt. Those whose impairments are judged severe enough to prevent them from working at all will receive a higher-rate ESA and will be placed in a support-group where they receive the benefit without any associated conditions.

The Citizens Advice Bureau (CAB) found that the WCA is failing to properly determine capacity to work, and is frequently



placing people in the wrong categories, based on a clunky and insensitive medical assessment. All too often, people who should not reasonably be expected to work as a condition of benefit are being put in the employment-group or, on occasions, refused ESA altogether. Headline grabbing incidents include individuals with advanced Parkinson's, multiple sclerosis and severe mental health problems being found fit to work.

Such illogical outcomes can easily be rectified,

given that they fly in the face of common sense and good medical judgement. What is particularly concerning is the evidence that the medicals are failing to account for symptoms which vary from day-to-day, and are insensitive to the complexities of many conditions. Critically, the assessment takes the form of a number of closed questions, providing no

opportunity for the benefit claimant themselves to explain the impact of the illness/impairment and associated societal barriers on their daily lives. This is patronising, disempowering and a complete rejection of social model thinking. As David Harker, Chief Executive of CAB, concludes: "Seriously ill and disabled people are being severely let down by the

crude approach of the Work Capability Assessment."

This finding matters a great deal – especially as all existing Incapacity Benefit claimants will shortly be migrated onto ESA. The flaws and rigidity of the WCA needs to be highlighted and rectified, and the CAB's call for a complete review of the WCA process should be echoed by the disability movement. Further, broader questions should be asked – and loudly – about whether an approach that crudely divides disabled people into different categories, that is based on medicalised notions of capacity, and which introduces work-related conditionality for disabled people, is the right one. These are questions which I will continue to pose to all who will listen.

- The full CAB report can be downloaded from [http://www.citizensadvice.org.uk/not\\_working](http://www.citizensadvice.org.uk/not_working)

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# politics

## One more in the House

Paul Maynard is the new Conservative MP for Blackpool North and Cleveleys. Speaking hours after being elected, he told **Sunil Peck** he was "honoured" to have the opportunity to make a "real difference" to people's lives

I think I've shown that having a disability should be no bar to getting elected, especially having a disability like cerebral palsy (CP), where people might not understand what it is and might think that you're learning disabled."

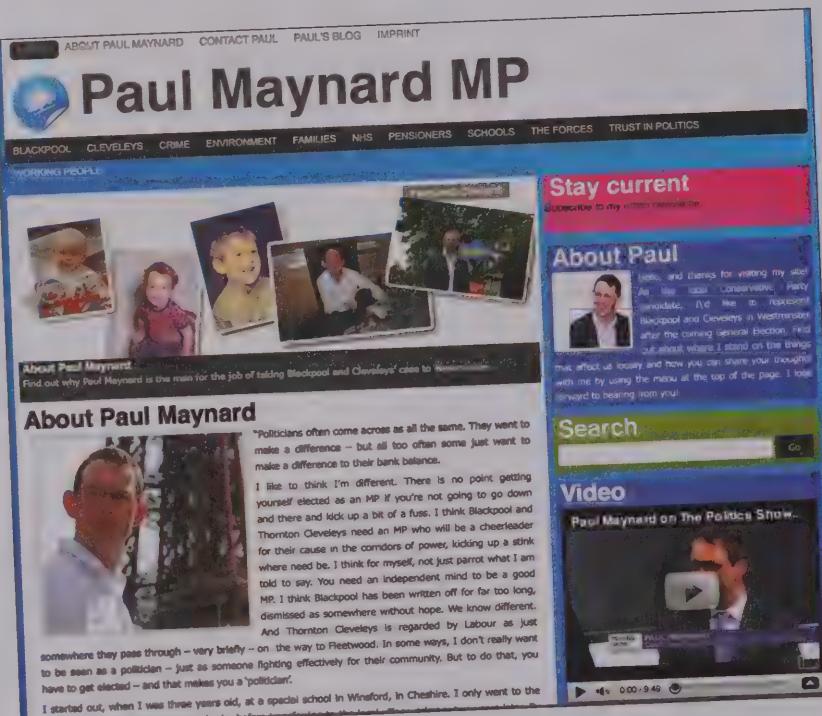
Paul Maynard, the new MP for Blackpool North and Cleveleys, is a former adviser to Conservative shadow health secretary Liam Fox. An Oxford graduate, he was beaten by Vince Cable for the Liberal Democrats in Twickenham in the general election of 2005. His new seat, which he won for the Conservatives with a majority of more than 2,000, had been held by Labour since 1997.

Because of his CP, doubts about Maynard's ability to work as an MP did surface during the election. He says these were hurtful but that it was only among a small minority of people. "Most of it was not so much based on hate but ignorance. Some people questioned

my ability to manage a public meeting. I'd get: 'If he's always drunk, how can he serve as an MP?'

According to Maynard, the significance of his disability only became apparent to him as the campaign went on.

"If you'd asked me six months ago, I'd have said that having CP made no difference at all. But with my experiences over the past few weeks, I've felt an incredible sense that I'm breaking a glass ceiling.



"The number of people who've come up to me with a disability or whose children have special needs and have said how pleased they are to see me not being afraid to enter the public arena has made me feel quite honoured."

Other disabled politicians, notably David Blunkett, have been criticised for failing to exploit their positions to bang the drum for political rights in Parliament.

So as someone who has become aware of the

significance of being a disabled MP, will Paul Maynard be any different?

"I don't want to pigeon-hole myself as a politician who only deals in disabled issues," he says. "Disability issues and long-term health conditions are massively important."

"Mine is a constituency with a very high number of people with a long-term medical condition, but topics like tourism, regeneration and poverty are incredibly important too. I've been elected by the people of Blackpool North and Cleveleys, not by the disabled community. That doesn't mean I shouldn't involve myself in issues relating to the disabled community, but I shouldn't allow those issues to define me as a politician because I have much more to say on a wide range of issues."

Paul Maynard's success in Blackpool is still sinking in, but he has no doubt that he'll be able to hold his own.

"I've heard stories about how the Commons can be a cruel place, but I hope it won't be. I'm used to debating in public and it doesn't hold any fears for me. If anybody tries to make fun of me in the

**I've been elected by the people of Blackpool North and Cleveleys, not by the disabled community**

Chamber, they'll get the sharp end of my tongue pretty damn quick."

Paul hopes that if he proves himself an effective politician, his poll victory will lead more disabled people to enter Parliament. But apart from doing his bit to overturn public mistrust of politicians in the wake of



MANCHESTER EVENING NEWS SYNDICATION

**Paul Maynard on election night: "Maybe I'm going there as an idealist: I make no apologies for that. I believe in optimism."**

the expenses scandal, what else does he think he offers?

"If I feel that ministers are listening to me on issues where I know what I'm talking about when I stand up to speak, if I can demonstrate that I understand policy detail, policy framework, and how to make people's lives better, that to me will be a success.

"Maybe I'm going there as an idealist: I make no apologies for that. I believe in optimism and looking on the bright side and I want to make change, so I'm going to give it a go."

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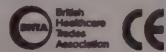
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# mediawatch

**A**fter the introduction of the Autism Bill, the first ever disability-specific strategy in the UK, which, at the time of going to press, is still awaiting Royal Assent, advertising campaigns have been rolled out and television has responded by making autism a priority in its programming.

However, while autistic rights campaigners say that it is hugely refreshing that people are getting a much-needed "post-Rain Man" understanding of the condition, accuracy and sensitivity to subject has been hit and miss.

*Young, Autistic and Stagestruck*, a Channel 4 documentary following the progress of a stage production put together by young people with autism, was broadcast last month. While the first episodes seemed to focus on the parents' and drama teachers' struggles to overcome the children's impairments, the latter ones were far more positive, showing a collaborative reach towards the children's final goal.

"There were some moments during the show where I really wanted to throttle the producers, to yell that that's not how it happens!", says Anya Ustaszewski, an autistic artist and writer.



Eco-housing, rah-rah skirts, whoopee pies, Bulgarian holiday homes, we British love to be up with trends. But, let's be honest, not many of us would expect autism to have become "popular". But **Cathy Reay** discovers that it's been in the media spotlight so much this year that campaigners say audiences are becoming more knowledgeable

Meanwhile BBC3 is currently midway through its first *Living with Autism* season, a series of programmes including *Autism and Me – One Year On*, *Autistic Driving School*, *Autism Disco and Me* and *The Autistic Proms*.

Though generally well-received, it seems to be a concern that some of these programmes are not being

broadcast for the right reason. Anya explains: "Sometimes I wonder what the motivation is behind showing people these things? Like *Autistic Driving School*, people with autism learning to drive, what general audience wants to see that? Are they playing with the tragedy of it, or what?"

Russell Stronach, Co-Chair

of the Autistic Rights Movement (ARM) UK, agrees: "I hope people can see the personalities behind the [people] and not just see them as victims. I hope it helps to combat stereotypes and that, in the case of *Young, Autistic and Stagestruck*, the audience will be able to respond to the parents' attitudes on the show."

While the new bill has clearly set the precedent for the media's coverage of autism, it's shock advertising like the Autism Trust's "Hello Boys" election campaign that put autism directly in the public eye in the first place.

The advertisements, which were posted on billboards around the UK at the end of March, were targeted towards political leaders. They featured charity chairperson Polly Tommey with her top off and the slogan "Hello boys, autism is worth over 6 million votes.

It's time to talk..."

Russell and Anya think Polly's risqué advertisements, which received an immediate response from all three major party leaders, may have fed broadcasting a new topic to explore.

"Though it's not for a great reason, Polly getting her top off almost definitely raised awareness," says Anya.

Polly, who has a daughter with autism, said her intention was to get parties to put the impairment in their manifestos. She told *Disability Now*: "Our advertising people said we

needed something striking so that's how it happened. The three main party leaders put statements out following the ads but disappointingly Gordon Brown was the only one to include autism in his manifesto."

The Goth, editor of *Asperger United* magazine, said that, regardless of why, he is thrilled to see autism in the media: "I don't think a lot of people realise how

difficult day-to-day life is. We spend a lot of time being blamed for our behaviour which is unfair as we don't experience things in the same way."

- If you missed any of the programmes discussed in this piece you can catch up online via BBC iPlayer (search "Living with Autism") and 4od (search "Young Autistic and Stagestruck").

#### → Have your say

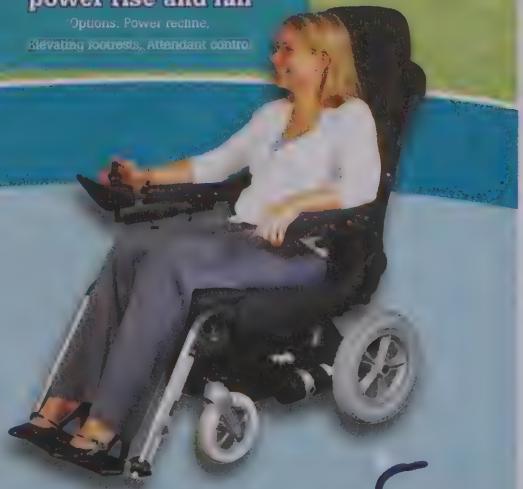
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# disabilityrights

## Dear new Prime Minister



Disabled activist and rights campaigner **Alan Holdsworth** has a few well chosen words for our newly elected Government

I've been looking back over the 25 years I've been involved in the disabled people's movement and come to a simple, though to you politicians, perhaps not so simple conclusion. That the best ideas come from disabled people themselves.

The social model of disability took the blame away from us and onto a society that fails to address our requirements, which creates inequality.

Independent living has begun to close down the asylums and inhumane institutions and brought us back into the community where we belong, helping us to direct our own services and care.

Direct action by disabled people changed the way we were seen, moving us onto the political agenda.

The passing of the Disability Discrimination Act laid out a platform for us to advance our rights. The drive for inclusive education has meant that special schools are closing and the end of segregation is in sight.

All ideas which came from disabled people.

By ignoring the strong voice of disabled people you as a Government risk wasting money and making things a lot worse for us and our families.

When will you finally get that we are the experts? Not doctors, not bureaucrats, not para professionals and, dare I say it, not carers.

Your new Government needs to hear our ideas, create partnerships and work with us to make equality a reality for disabled people in Britain.

In order for this to happen you need to rebuild the disabled people's movement by doing, in the first instance, two things.

First, pass a statutory mandate that all local authorities in the UK must have a cross-impairment coalition of disabled people that they consult and work with. This should be primarily funded by the local authorities and run and controlled by local disabled people. These



coalitions' main tasks would be to set up consultation forums on the development and improvement of local services, to review and scrutinize local policy and planning, to develop and conduct disability equality training for all local authority personnel and to create time and space and resources for disabled people to come together to resolve issues and influence policy and action.

You should also create and support centres for independent living in every area. These centres should be run and controlled by local disabled people. They

should offer information and referral, peer support, independent living skills training and advocacy.

They should also provide and run self directed support services.

Both these initiatives should be linked to national organisations of disabled people.

If this policy was enacted it would reduce waste on creating things we don't need. Without us you are swimming in a sea of confusion.

So congratulations. Now are you up for a strong productive partnership or are you afraid of your people?

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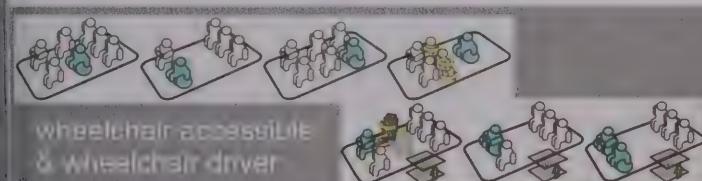


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# worldview

## War and peace in the Indian Ocean

In May 2010, Sri Lanka, the Pearl of the Indian Ocean, celebrated the first anniversary of the end of the 26-year civil war. **Susan Bennett** has lived with and worked as a volunteer alongside its people since 2006. Here she describes the challenges for people with sensory impairments living in remote areas.

**A**s you crest the ridge high up in the centre of Sri Lanka in the Knuckles Mountains, blue skies stretch across the entire horizon, etched by the clear lines of sharp peaks and steep rock-faces.

A precarious single-track road, deep with potholes, leads the way to a remote village down in the deep valley bottom. Luscious wavy lines of paddy fields, shadowy grey shapes of water buffalo grazing the pastures, and occasional

bent stick figures of local villagers working the fields with hand ploughs and machetes, show how little life has changed in the last hundred years.

As I arrive with my partner from the Abode Trust, Sidanthe, the welcome is

unconditional for this is our second home and we easily slip into its warmth. Members of the community arrive to greet us, and invitations to eat and sleep in their homes flow fast.

We admire the new babies born in the last few months



**Kumar has been deaf since birth and has had no access to hearing support. Hearing the torrential rain outside, his face lights up. Then he smiles, a smile that dazzles the room**

and the stacks of newly bagged grain, proof of the success of the recent paddy harvest. There's news of a death the previous week, a stillborn child and of the terrible cough and debilitation of an elder.

In the middle of a thunderstorm, Banda brings Kumar to see us. They've come from the other side of the valley under two huge umbrellas. Lean and with the erect posture of the military, Kumar's on leave from the army for the New Year. Round his neck he wears a decommissioned cyanide capsule taken from a Tamil Tiger.

Kumar has been deaf since birth and has had no access to hearing support. I show him the aids I've brought for him, I fit them and turn them on.

Hearing the torrential rain outside, his face lights up and he cocks his head to one side with attentiveness. Then he smiles, a smile that comes from his heart and

dazzles the room.

Everyone begins to talk and cry at once, in what Kumar must have found an assault of sound. It's a moment of excitement, humility and wonder. And all because of a pair of second-hand hearing aids donated in the UK.

It began in 2006 when I was taken to the village by Sidanthe. I learnt not to recoil in horror at the size of the crickets or at leeching. I got used to eating with my fingers, sleeping on the hard floor amidst unfamiliar bodies, and making my toilet in the jungle, and I found ways of washing discreetly in the river while subject to many curious eyes. Since then we've been working with the villagers through war and peace and have become members of the community, accepted and expected to make a contribution.

I well remember the moment one of the village leaders accidentally tried my glasses on and found that he could see newsprint and the pictures in a bird book for the first time in many years. That led to us supplying second-hand glasses from the UK to the local people. And I recall the memorable day a deaf man was brought to meet me in the toddy man's (local liquor) house and the effect one of my digital

hearing aids had.

It was a surprise to find the villagers had little in the way of sensory aids. That's not to say there's no healthcare in Sri Lanka, but most of it's located in the main towns and cities and there's little beyond the basics for those who cannot afford to pay.

Glasses are unseen and even children struggle with old fashioned and inadequate analogue aids, unless their parents are rich enough to go private. In

**Life's too close to the limits of survival to devote time to any health matters that aren't immediately urgent or extreme**

this village and many others that's not even a remote possibility.

The peace and Tsunami funding have made little difference. There are rural health camps where doctors come to the remote areas every year but gaining access to state-funded spectacles or hearing aids is an onerous process and prone to attrition. You can gain bog-standard and ancient old-fashioned glasses or hearing aids from the state but few in the villages have the confidence,

persistence or the assertiveness to pursue their case.

Life's too close to the limits of survival to devote time to any health matters that aren't immediately urgent or extreme. Village people live isolated lives, are unused to dealing with officials, become humble and invisible when faced with professionals and have little literacy. To even consider the six-hour return journey to the towns and cities on the one bus a day is a step too far for most. So most disabled villagers with hearing or sight problems, adults and children alike, manage without help.

Over the years, as part of the Abode Trust, we've sought to bridge the gap by bringing used glasses from the UK, donated voluntarily by churches, individuals and the third sector to this village and others in the remote areas of Sri Lanka. We leave them with either the village leaders or the local Buddhist monks who supervise their distribution according to need.

The challenge now is to bring more glasses, digital hearing aids and, more importantly, a constant supply of batteries to the villagers.

- Find out more about Susan Bennett's work at [theabodetrust.com](http://theabodetrust.com)

# onetowatch

## Lucy reaches for court stardom

Lucy Buxton may only be 17 but she's already slam-dunked the sports scholarship of her dreams. Hoping to represent England in the European basketball Championships 2010, she checks in with **Cathy Reay** for a quick grilling on her motivation and goals.

### What's the best thing about being disabled?

I like being able to take out my cochlear implant at night and not have any noise interrupt my sleep. It's also helpful when I'm arguing with my parents!

### What funny things get said about your impairment?

Nothing, really. Mostly, people misunderstand me.

### What makes you angry?

I'm a perfectionist so if I'm not winning I get annoyed. I also tend to feel bad if I've taken an exam or something and I know I haven't done as well as I could have. When I see discrimination in action, too, I get really angry.

### If you were Prime Minister, what would you do to improve things for disabled people?

I'd increase funding for disabled people to be given more opportunities to take part in regular life. For example, deaf children often go to specialised deaf schools because there isn't always the support needed for them to attend a hearing school. I'd also introduce exchange programmes, as I went to Australia recently on one and loved it.

### What invention could make your life better?

A solution to deafness! Failing that, a waterproof cochlear implant would be really useful, as you get quite sweaty when doing exercise. Better batteries would also be handy.

### What do you like most about basketball?

Winning! Team spirit is great too, coming together to achieve a goal.



### What do you like least about basketball?

Losing in a tight game, as it gets really frustrating.

### Who's your favourite disabled person ever?

Tanni Grey-Thompson. She's so inspirational as an athlete. She made people realise that being disabled doesn't stop you from achieving your goals.

### Do you have any special or hidden talents?

Sport is my talent, but I've also got really flexible thumbs!

### Can you sum yourself up in ten words or less?

Positive, hardworking, energetic, competitive, enjoyable, caring chatterbox!

### → Who do you think is One to Watch?

Send us your nominations for likely lads and lasses who could answer our 10 questions. They can be rising stars in any field of entertainment, business, the media or beyond

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# Warwick

## I'm calling the shots

At 40 years of age, Warwick Davis already has a screen CV that would make most British actors green with envy, having appeared alongside some of the biggest Hollywood names in a string of box office smashes. Now, having just completed an autobiography charting his life and career to date, along with an upcoming primetime television show, he tells **Paul Carter** that the pace of his career shows no sign of abating

**R**emarkably, it was as an 11-year-old boy back in 1981 when Warwick landed his first big break largely thanks to his grandmother, who heard a radio advert in the London area calling for short people to appear in a new film being made at Elstree Studios in Hertfordshire. And what a break it was. The film in question happened to be *Return Of The Jedi*, the third instalment of what remains the biggest movie franchise of all time – Star Wars.

"[My Grandmother] called my Mum and told her she'd heard this advert and what did my Mum think," explains Warwick.

"As soon as my Mum heard the words *Star Wars* she thought 'oh well Warwick's going to love this!' as she knew I was a huge fan of the movie.

"She called up the studio and they said we were actually too late because they had been inundated with calls from people. I don't know what she said, whether she offered them cash, but they had a change of heart and said 'bring Warwick into the studio,

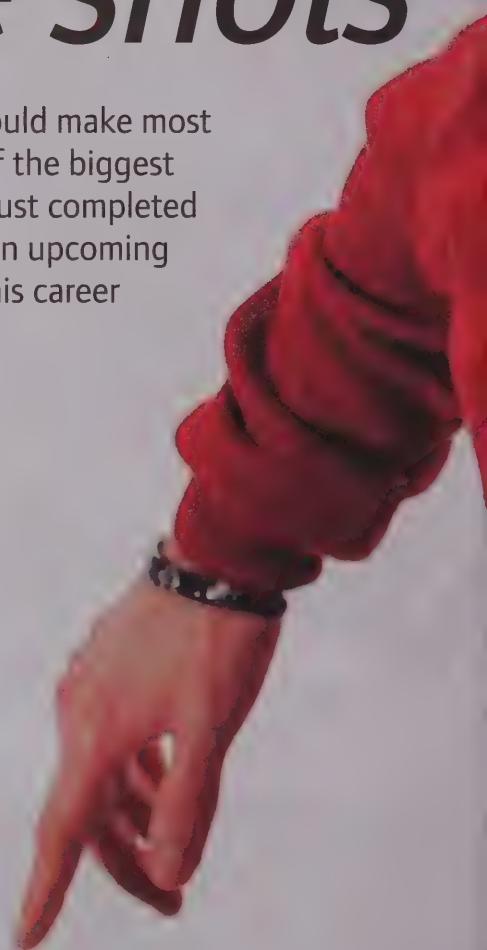
and we'll meet him'.

"So I went up to the studios full of enthusiasm and excitement and they took one look at me, then I only stood 2 feet 11 inches tall, and they said 'great you're going to make a good Ewok, go and get yourself measured up for a costume'."

More good fortune was to fall Warwick's way. Actor Kenny Baker, who already played the role of robot R2-D2 in the series, was due to take the role of the lead Ewok, Wicket. However, Baker fell ill the day shooting was due to take place, meaning the young Warwick was thrust into the limelight, albeit beneath a furry costume.

"Basically, when you watch Wicket, that's an 11-year-old boy on the *Star Wars* set – that inquisitive nature, that kind of wide eyed wonderment which came through in my performance really," he says.

Twenty nine years later, it is clear that Warwick's enthusiasm for his work and his career is as strong as ever. He talks with such an infectious enthusiasm about





TERRY HARRIS

all of his roles that is easy to see why [Star Wars writer and producer] George Lucas picked him out for the lead role.

Drafting in Warwick to play Wicket was not to be Lucas's only significant act on the young actor's career. He would go on to achieve international stardom in the 1988 film *Willow*, co-written and produced by Lucas, in which Davis played the eponymous sorcerer alongside Val Kilmer.

Warwick has since gone on to appear in a number of cult and commercially successful films, including several *Harry*

*Potter* instalments, the *Leprechaun* series and the *Hitchhiker's Guide To The Galaxy*.

When the topic comes around to the type of roles he has played, Warwick is philosophical yet unwavering in his outlook, stating that he is more than happy being cast in sci-fi or fantasy genre films, usually playing what he calls "the slightly odder, alien kind of creatures or off the wall characters."

"I love doing all of that and would never deny doing any of that work at all because I'm a performer through and through and to have the chance to perform, albeit under make-up that takes four hours to apply, or a furry suit or what have you, that's what I live for, the performance side of things," he says emphatically.

"But I don't think that any of that is any less important as far as acting goes than playing a role in *Macbeth*. I strive for perfection, and every job I do I try to do as best I can."

So, with that in mind surely he would like to play more roles that didn't necessarily require being short?

"Yeah I do, of course, that would be →

a lovely ambition and I suppose it's one that does sit in the back of my mind," he says.

"There are many roles that I see go through cinema and television and I think 'oh I'd love to play that character', but it wouldn't work because I'm short and it doesn't fit in with that particular film script.

"So yeah, I do strive for that and it's lovely when I'm offered a role as I was in the movie *Ray*, where I was playing somebody who happened to be short, but I didn't necessarily have to be short for the part.

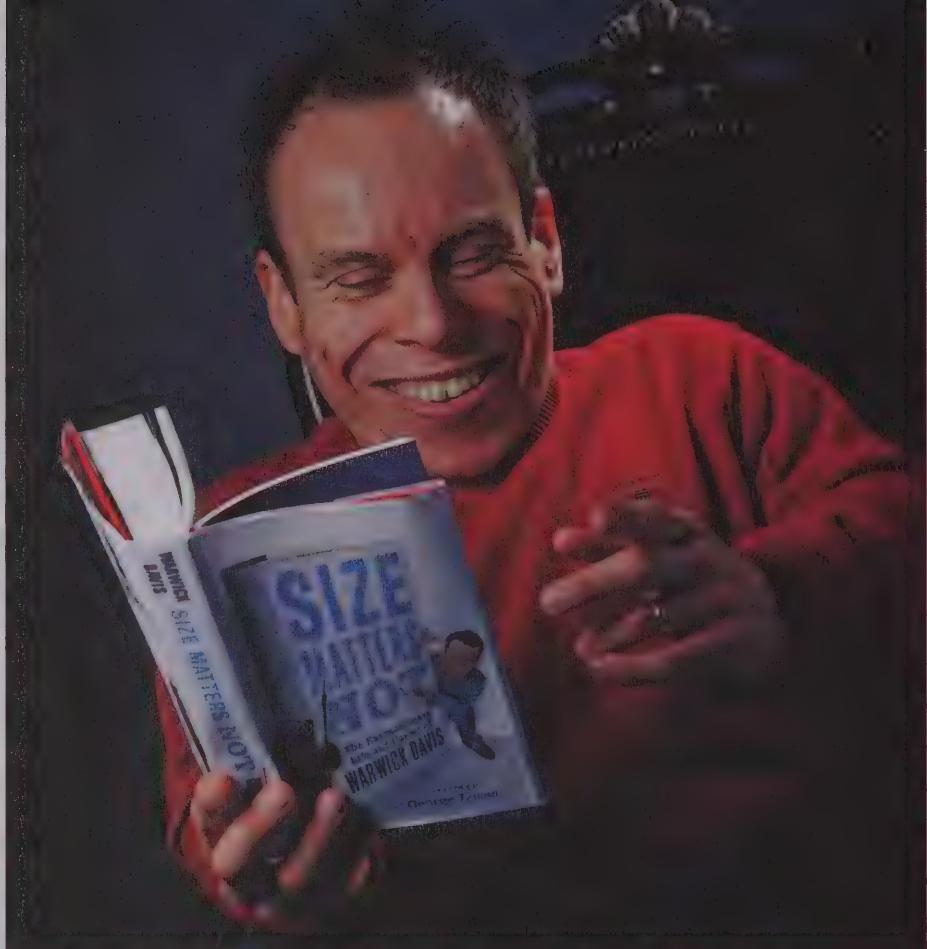
"They're quite nice roles to have. It'd be great to have it but I'm not waving the banner hoping that comes along. It's just having the opportunity to perform and as long as it's not something that's exploitative or in any way demeaning, then I'm more than happy to be there."

However, it's Warwick's next role that may yet prove to be his boldest to date, as he begins shooting a pilot for a BBC/HBO co-production which is to be written and directed by Ricky Gervais and Stephen Merchant, the duo behind *The Office* and *Extras*.

Warwick explains that the idea came out of several filmmakers approaching him and his family about the prospect of doing a fly-on-the-wall documentary around his life, something he says never particularly appealed.

"But it did get me thinking, there's obviously something I can do here, so maybe I should do my own documentary, where I can remain completely in control of it. But wouldn't it be fun to slightly manipulate it so it doesn't become a documentary any more, and make it funny? Wouldn't it be good to point out to the world all the funny things that occur when you're a little person in this big world?"

The result is a comedy spoof



## Then I only stood 2 feet 11 inches tall, and they said 'great you're going to make a good Ewok, go and get yourself measured up for a costume'

documentary called *Life's Too Short*, which will initially be screened on BBC2, in which Warwick will play the lead role.

"It's me as Warwick Davis, though I'm playing a kind of different version of myself, a rather fame hungry kind of person," he explains.

"He loves recognition, he craves the fame element of being an actor, but he's a bit down on his luck. He's getting divorced but he does have the same career background as me, but the family side of things, the personal set-up, is fiction."

Warwick freely admits that the show is likely to "strike a few nerves", but insists that the aim is to turn the spotlight back onto the viewer, and that he is very much the one calling the shots.

"Being a little person, I own the joke," he says.

"It's more often than not making the world around me look like they're the ones who are idiots if you like. Not only will it make people laugh, but it will also give people an insight into what the world as a little person can be like, and I think ultimately the world of disabled people and the way that you can be treated when you're slightly different in society."

As well as his work on screen, Warwick has worked hard behind the scenes to improve the situation for short actors, notably through his agency, Willow Management, which he established with his father-in-law Peter Burroughs, himself a successful short actor, in 1995 and which now represents over 100 clients.

"We started Willow Management mainly out of my father-in-law's discontent at that time at how he was being represented as a short actor," he explains.

"He's 4 feet 6 and he's been in the

business many, many years and was dissatisfied with the pay and being treated like a second class actor and so he said if everybody stuck together, all the little actors in the country, we could hold out for more money and better treatment.

"We've turned the business around. When we talk about our clients and we talk to production companies and directors, we call them short actors. They're not dwarves, they are short actors. They have their own prominence and their own talents and their own skills which we represent in them."

Along with work still ongoing on the seventh and final Harry Potter film in which he plays two roles, Warwick is also finding time to



TERRY HARRIS



squeeze an extensive book tour around the country, signing copies of his autobiography for fans.

"I'm firmly of the belief that you're only as successful as your audience makes you," he says, "and this is my way of saying 'cheers, thanks a lot'."

With everything on the horizon, is he pleased with where he finds himself?

"I can't quite believe it to be honest," he says.

"I never could have predicted this would happen."

"That's what's so wonderful about being an actor, you just never know. A wonderful opportunity presents itself to you and you're doing something completely different."

"It's very exciting." ■

• *Size Matters Not*, published by Aurum Press, is available now.

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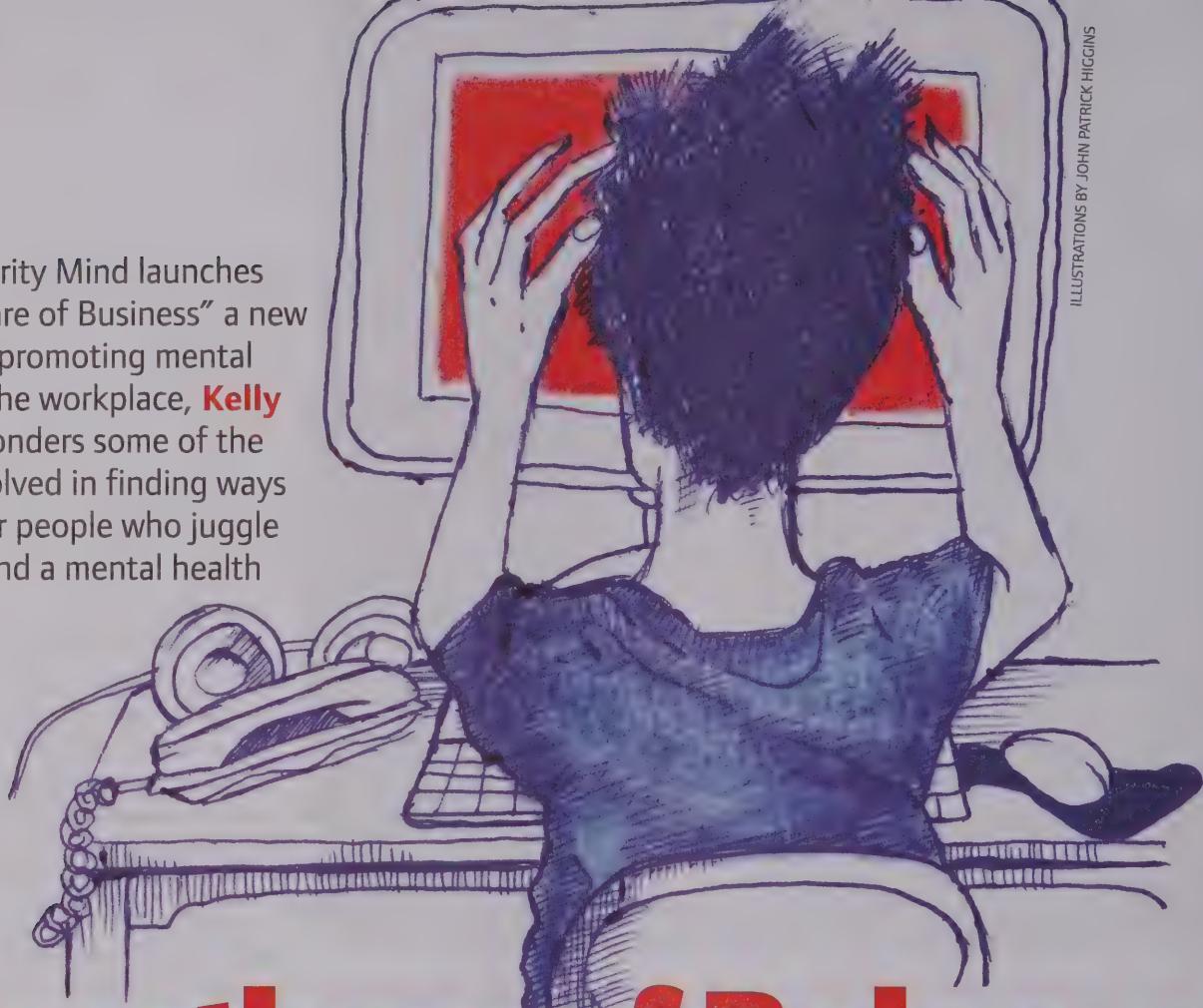
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As the charity Mind launches "Taking Care of Business" a new campaign promoting mental health in the workplace, **Kelly Mullan** ponders some of the issues involved in finding ways forward for people who juggle their job and a mental health condition



# Questions of Balance: Work and mental health

**D**epending on the work environment and the job, employment can cause, exacerbate or ameliorate mental distress.

According to Stand to Reason's "Glass ceiling" campaign, only 20 per cent of people with severe mental health problems are employed, compared to 65 per cent of people with physical health problems and 75 per cent for the whole adult population. Yet we have the highest "want to work rate" of any group of unemployed people with up to 90 per cent wanting to work.

Peter Beresford is a professor of social work at Brunel University and

has a mental health condition. He says "Being in a job can be a great thing. It's great for me! But employment should be a right not something used to bring people in line."

"When the Government says, 'we've got to get a million people off benefits' there is the implication that a lot of them are malingering. There is institutionalised stigma yet anti-stigma campaigns are aimed at Mr & Mrs General Public."

There have been more developments in mental health and employment policy in recent months than at any time in the last decade. In understanding this plethora of recent

pronouncements on work and mental health, New Horizons, published in December 2009, is key. New Horizons is a cross-government programme aiming to improve the mental health and well-being of the population and improve the quality and accessibility of services. It stresses the economic benefits of getting people with mental health conditions into employment.

Many of the ideas in New Horizons come from research by Lord Layard, an economist at London School of Economics. His arguments for Increasing Access to Psychological Therapies (IAPT) are largely economic, based on the idea that greater access

to therapy will take people off welfare and save the state money. Cognitive Behavioural Therapy (CBT) is seen as particularly effective.

Layard put the cost of mental illness to society at £25bn a year, over two per cent of GDP. New Horizons estimates that the full cost to the economy of mental illness is "around £77bn, mostly due to lost productivity."

Service users are worried about conflicting goals implicit in IAPT. The aim of a good therapist is to see a person's condition improve but the success of IAPT will be measured by whether that person comes off benefits and into work.

For the prospect of moving into work to seem like an opportunity rather than a threat, a lot still needs to change. Stigma, the disclosure dilemma, barriers to employment, and the postcode lottery of NHS mental health services must be addressed.

Professor Beresford says: "We need a rights based approach to disability and employment addressing barriers and exclusion. Is the labour market accessible or discriminatory? What helpful, sensible, sensitive, reasonable readjustments can we make? The benefits trap needs to be addressed so

people can easily get back to where they were if a job doesn't work out. Our approach needs to be methodical, down-to-earth, and legally based.

"What we need is a model of Independent Living. We should have support as a right so we can do the things others can do. It's not about special pleading; it's about equality and equal access. Access to Work is a realm to be developing, opening up possibilities."

Take up of Access to Work by people with mental health conditions has been low. From April to September 2009, only one per cent of those who received support cited mental health conditions as their primary disability.

For the aims of New Horizons to be realised, investment in support services is needed but in the current climate it seems likely that funding for mental health services will be cut. From next year, the money for IAPT going to primary care trusts will not be ring fenced. There is also the fear that the well-being agenda of New Horizons will mean a dilution of the quality of provision for people with serious mental health problems.

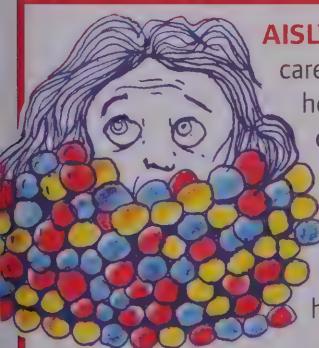
And just as the carrots enticing us into work are looking thin on the

ground, more sticks are popping up. According to a CAB report on Work Capability Assessments (WCA) published in March, disabled people including people with severe mental health problems are being deemed fit to work and losing their benefits. Professor Beresford calls this "shocking, crude and cruel", and says: "The mechanism for assessment is punitive."

The WCA was revised again in April with the sections relevant to mental health cut in half. Mind's Chief Executive Paul Farmer said: "We have seen some shocking examples of people who cannot reasonably be expected to enter any workplace being assessed as fit for work.

"People who are found fit for work will have their benefits taken away and will be forced to look for work, some without hope of an employer ever taking them on."

*Disability Now* columnist, Ruth Patrick, asks: "Do we have to be so obsessed with work?" Paid work is not always a transformative experience especially if it's minimum wage. There are different forms of involvement like parenting or voluntary work. These contributions should be valued as much as paid work."



**AISLYNN**, 31, was working as a Community Family Worker, supervising contact between children in care and their families. When she was signed off work for a few months with depression and SAD her employers called a meeting: "They said that as I was still in my probationary period and they couldn't see me improving, I wouldn't be allowed to finish my probationary period."

Aislynn was unable to claim benefits but luckily she had a mortgage protection arrangement or she would have lost her house.

Aislynn's next job was in a nursery for 18 hours a week. As winter approached, Aislynn began to feel very low with SAD. Her employers provided her with counselling but then called her in to "discuss options".

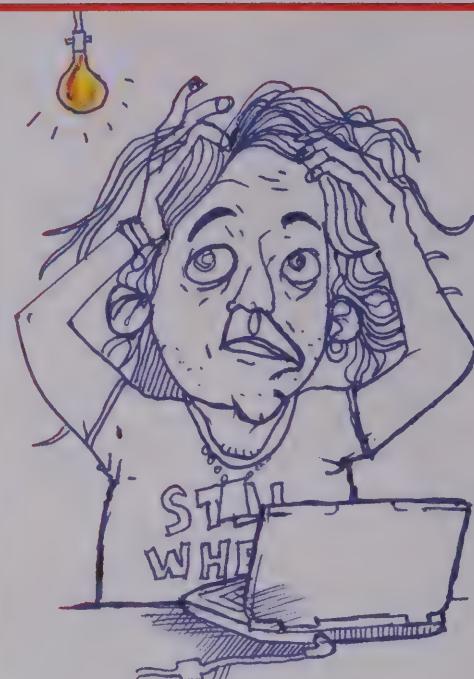
"They said that I'd have to leave even though I had a note from my GP saying that I'd be ready to go back to work in four weeks time. They were worried that the children would be at risk, which I found extremely upsetting."

For the past three years, Aislynn has worked as a sessional worker for her local council although she is currently signed off. She likes sessional work better because it's not full-time and she doesn't have to meet deadlines.

"If I think about going for another job, it worries me. I think I will always be asked to go."

**JENNY\*** has worked in the past but when she developed depression and anxiety she applied for ESA. Despite two GPs, a psychiatrist and a senior nurse stating that she is not able to work or seek work, a 54 minute assessment and a report written in the remaining six minutes disagreed, and she was refused. Jenny feels that her condition has been made light of and the refusal of ESA has caused her distress, severely impeding her recovery.

**MICHELLE\*** has a diagnosis of paranoid schizophrenia, severe anxiety and depression. She has very poor short-term memory, relying on a task list to get through daily routines, and avoids social contact and going to new places due to severe anxiety and panic attacks when she is unwell. Michelle had to fight on appeal to qualify for ESA, but under new proposals would likely be assessed as fit to work.



**PHILIP\***, 48, worked as a tour production manager, going on the road with bands, before taking a job at a live music support company.

The office had no natural light – just one neon strip light. “I asked time and again for another light and I asked for a light box to help with my SAD.” Philip’s complaints to his company boss and efforts to relocate the office met with silence or refusal: “They said ‘we don’t do things like that here’.”

Philip told his GP that sometimes when he was cycling to work he felt like cycling under a bus. His GP

arranged for a local crisis team to visit Philip at home and he was impressed with the support they provided.

Although Philip had mental health problems prior to taking the job (he was diagnosed with schizophrenia and sectioned during the 80s) he feels that his poor working environment made his problems much worse.

Philip left after 18 months. He didn’t take them to a tribunal but he did tell them that the working environment contravened regulations. The office is now much better but as Philip says: “I had to be ill for it to change.”

Philip, now a full time parent, still does some tours and writes creatively. Of his previous job, he says: “Work nearly killed me. It was the worst time of my life.”

On disclosure Philip says: “Do I tick the box or not? I once made the mistake of telling a band about being sectioned, it spread like wildfire and stopped me getting work. I now never disclose.”

**STEPHEN**, 25, was diagnosed with depression five years ago and has worked in a call centre for the past two years. A couple of months ago he experienced a “setback” and this started to affect his work – he was turning up late and couldn’t concentrate. Stephen says: “Work wasn’t a direct cause of my depression but it was a trigger. I was embarrassed as I was tearful, which was hard as I’m a bloke and there’s stigma around weakness in men.” Stephen had not disclosed his depression at work, but his line manager recognised there was a problem and she referred him to occupational health who arranged for counselling sessions through the Employee Assistance Programme. His manager asked if his hours were a problem and said, “We want to be as flexible as possible”. Changes were made quickly and he now does two hours less a day. Stephen is logged onto a system monitoring calls so he couldn’t take breaks as and when he needed them. Again his line manager arranged for this not to be a problem. She also respected Stephen’s wishes that his colleagues weren’t told about his mental health problem. This was a concern for Stephen as he had witnessed bullying of a colleague with a mental condition. “My manager has been really great and takes the time to check I’m ok. I’m surprised about how good they’ve been, I thought they might try to manage me out of the company but I’m still not sure I’d disclose my depression to future employers.” ■

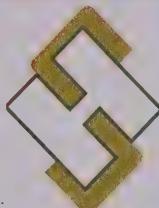
CALLS : 12



\*Names have been changed. • Case studies provided courtesy of Mind. ..Sign up to Mind’s campaign at [mind.org.uk/employment](http://mind.org.uk/employment)



# Sussex Health Care



Sussex Health Care is an award winning group of care homes that were founded in 1985.

Sussex Health Care now operates 16 care homes, predominantly in the West Sussex area, providing nearly 550 beds, incorporating specialist care provision including care for older people.

## Orchard Lodge, Dorking Road, Warnham, West Sussex RH12 3RZ

Orchard Lodge, just outside Horsham, West Sussex, provides care for adults with learning and physical disabilities. This specialist care home with nursing combines the latest technological facilities with a safe and comfortable environment. Activity rooms are available to all service users along with sensory and physiotherapy rooms.

Hydrotherapy services are available in the swimming pool and spa with multi-purpose rooms for structured activities.

## Wisteria Lodge, Horney Common, Nutley, East Sussex TN22 3EA

Wisteria Lodge in Nutley, East Sussex, caters for young people with physical and learning disabilities. The home offers superb purpose-built facilities with track hoisting throughout. Each single room provides en suite facilities. A spa pool is available to all service users along with sensory and physiotherapy rooms.

### STOP PRESS

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**Orchard Lodge, Warnham, near Horsham RH12 3RZ and Wisteria Lodge, Horney Common, Nutley TN22 3EA**

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BEECH LODGE (Physical & Learning Disabilities) Horsham 01403 791725

HORNCastle CARE CENTRE (Acquired Brain Injury & Neurological Conditions) East Grinstead 01342 813910

KINGSMEAD LODGE (Physical & Learning Disabilities) Horsham 01403 211790

NORFOLK LODGE (Learning Disabilities) Horsham 01403 218876

ORCHARD LODGE (Physical & Learning Disabilities) Warnham 01403 242278

RAPKYNS CARE HOME (Adult Care & Neurological Conditions) Horsham 01403 265096

RAPKYNS CARE CENTRE (Physical & Learning Disabilities), Horsham 01403 276756

WHITE LODGE (Learning Disabilities) Purley, Croydon 020 8763 2586

WISTERIA LODGE (Physical & Learning Disabilities) Nutley, Nr. Uckfield 01825 714080

For further information or to arrange a visit, please contact Corrine Wallace,  
Head of Operational Care Services Tel: 01403 217338 • Fax: 01403 219842  
email: [corrine.wallace@sussexhealthcare.co.uk](mailto:corrine.wallace@sussexhealthcare.co.uk) [www.sussexhealthcare.co.uk](http://www.sussexhealthcare.co.uk)



# yourviews

## High heels for wheelchair-users

I always enjoy reading Lara Masters' pieces in *Disability Now*. She has such an entertaining and thought-provoking style, and always looks great in fashion photos. But I was especially interested in her article featuring Dame Tanni Grey-Thompson in the April issue ("Tanni on track for The Lords").

In the article, Tanni commented that she can't wear high-heeled shoes, because when she does, her feet roll over sideways. I know what she means, because for a long time I found myself in a similar situation. I've asked wheelchair companies about supports for heels and they've never had any ideas. But recently, with the help of a friend with some practical skills, I found a solution.

The answer we've come up with is a two-part system. The first part consists of a wedge-shaped cushion made out



of firm foam, which I insert underneath the front part of my normal chair cushion. With this in place, my knees are lifted about three inches or so higher than normal, so my legs are in a suitable position for wearing heels.

The second part consists of a support for the shoes. This is essentially a vertical plate, firmly attached to the footrest and positioned so the heels of my shoes drop down behind it while the front part sits in front of it. This stops the shoes (and feet) from moving forwards or backwards. By making

the outer ends of the support plate higher than the middle part, it also holds my shoes in place in the middle of the footplate, and stops them either moving or rolling sideways.

The support system is a rather crude home-made affair, built from wood, but when painted black to match my chair, I think it looks smart, and I don't think anybody can tell

that it isn't a "proper" wheelchair component.

Since I started using it a year or so ago, I've had great fun getting all my old favourite shoes out of the cupboard (I never could throw them away!) and wearing them anew. And trips to the shops now always include the continuing quest for the perfect shoes.

If anybody wants to try copying the design, I'd be happy to supply details, sketches and photographs.

**Penny Thomas,  
Aberdeenshire**

### Disabled legend Churchill "traitor"

I'm disabled and a disability equality trainer, and I was shocked to see Winston Churchill being championed as a "disabled legend" in your last edition of *Disability Now*.

Churchill was committed to promoting racial purity and eugenics, and was very active (for example, in 1916) in trying to get Parliament to force disabled people with mental health issues and learning or cognitive difficulties to be locked up or sterilised. He therefore hardly qualifies as a disability legend.

How on earth did he get nominated and what credibility does *Disability Now* have when carrying an article recommending its readers vote for him? Surely you should be expanding our understanding of disability equality history not glossing over it. Shame on you!

**Laura Welti, by email**

### Tesco goes stale on home delivery ...

I'm disabled and I've been a customer of Tesco all my life. I depend on home delivery of my groceries but for the past few months my frozen food has arrived defrosted and my fresh food has arrived unfresh.

I've complained about this and had assurances from the store manager that it wouldn't happen again but it continues every single week. Trading Standards say my only choice is to shop elsewhere, despite the fact that I pay £300 a year for a service that promises to deliver fresh food. I feel demoralised. Have other readers experienced anything similar?

**Catherine Davies, by email**

### ... and demands pin number disclosure

Tesco in Redditch offers a service call for people in a wheelchair, but doesn't have a mobile chip-and-pin reader. That means you have to tell the assistant your pin number. I think that's wrong. If you offer a service, surely it shouldn't discriminate against people with disabilities.

In the evening, Tesco rang me to explain that none of its garages carry mobile chip-and-pin machines and asked why I couldn't get out of the car to pay. I had to explain that it took too long to get the wheelchair out and that I didn't use cash as I was once mugged. All I got was an "oh dear". So come on Tesco: get mobile machines or, if you can't, put out a sign to say so.

**John Warren, by email**

## Scooters: the debate continues

Why don't we demand compulsory training for cyclists, and call for more action against the one in five car drivers who use the roads without insurance?

The legal speed limit for mobility scooter-users using pavements is two miles an hour, and many scooters can't go any faster.

Compare this to the speed of a runner or cyclist on the pavement, and think about how many collisions they have with pedestrians each year. Think also about how many pedestrians collide with other pedestrians on the pavements, sometimes causing serious injuries.

Newspapers demonise scooters and are quite opposed to the regulation of cyclists. Of course it would be great if scooter training was freely available, as it is for cyclists, and if specialist insurance companies offered monthly payments to make their products affordable to all.

But before we provide more support for the stereotype of disabled people as too dangerous and unsafe to be allowed out on our own, thereby robbing many of their right to get to the shops and cashpoints, let's get our priorities in order.

**Dr Ju Gosling, London E16**

Mrs Findlay-Judge ("Four wheels good", Letters, *Disability Now*, May 2010) accuses me of "slagging off" mobility scooter-users. Not at all. I'm the Director of Policy and Campaigns for Mobilise, the charity that promotes mobility for all disabled people.

Many of our members use mobility scooters and we campaign constantly on their behalf, from lobbying transport companies to improve their policy on transporting scooters to ensuring that "shared surface" schemes take scooter-users into account.

Mrs Findlay-Judge's remarks suggest she thinks I'm non-disabled. In fact I am a quadruple amputee, which I reckon probably does qualify me as disabled!

Expecting users of mobility aids to behave in a way that's safe for them and for others isn't "slagging off", as she says: it's plain sense, and any responsible scooter-user would agree. It's your duty to keep the scooter under control because not everyone can hear or see you coming.

The writer asks what my

mother and I were doing when a scooter-user ran into us. Well, we were standing in a queue and it's not always possible for me to leap athletically out of someone's way if they don't brake in time! By the way, scooters do have brakes: the fact that some are operated "positively" (as in a car, where force is applied to the brake) or "negatively" (where the controls are released) is irrelevant. Saying scooters "don't have brakes" shows a dangerous lack of understanding.

Mrs Findlay-Judge adds that "disabled people can't answer back". Well, here I am. My job involves me in "answering back" every day to government, media and companies. I'm also happy to answer any further questions that Mrs Findlay-Judge or other scooter-users would like to ask about safe scooter use. You can reach me via the Mobilise website [www.mobilise.info](http://www.mobilise.info) or write to me at Mobilise National Office, Ashwellthorpe, Norwich, NR16 1EX.

**Helen Smith, Director of Policy and Campaigns, Mobilise**

### → Have your say

- write to us **Disability Now, 6 Market Road, London N7 9PW**
- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)

# andyrickell



## A ministry all our own

It's time, says **Andy Rickell** that "joined-up government" went all the way with the creation of a Ministry for Disabled People

**H**istorically, ministers are appointed to be the political leaders in each of the ministries or departments of government, like the Department of Health, Department of Work and Pensions etc.

Each minister recognises their position and status first and foremost by the department they lead, and is accountable for what it does. Although in theory ministers have a collective responsibility via the Cabinet, their departmental role often emphasises the importance of individual departments and what they do more than the impact they have as a whole government. It creates a silo mentality, where departments compete with each other and cooperation is undermined.

The whole machinery of government is inevitably a large and complex thing to manage. No simple solution is perfect, and the departmental approach at least has some sense – organising government on the basis of specialist areas

of activity. However this approach inevitably does not help those citizens who depend on the activity of several departments, and most of all it fails to help disabled citizens, who are more affected by or depend on the activity of more parts of government than any other citizen.

### One of the new super ministers should be a senior minister or secretary of state for disabled people

For some years now this weakness has been recognised and the solution is said to be "joined-up government" – where different parts of government at all levels cooperate – which for instance at the local level might be the NHS and social services. Sometimes things improve, but often it depends on individual civil servants to make it work, and overall disabled people's experience is that their lives are affected adversely by poorly

joined-up public services.

To make joined-up government work for disabled people and everyone else it has to be joined-up at the very top. Top ministers need to get their role and status from their responsibility to make government work for particular beneficiaries. Departments should be run by junior ministers, who should be accountable to senior ministers who would have cross-cutting power to knock departmental heads together to deliver for particular key groups of citizens. One of the new super ministers should be a senior minister or secretary of state for disabled people, because of the number of disabled people, our status in society, and the impact that government activity has on our lives.

It would require a leap of imagination for a new prime minister, but it would change government from

something run by bureaucrats to something more accountable to the people they serve.

### Departments compete with each other and cooperation is undermined

This type of ministerial joint working sometimes happens already. The Life Chances Ministerial Group is a group of ministers from different departments under the chairing of the Minister for Disabled People whose responsibility is to achieve the outcomes in the Life Chances report. But the ministers are junior and crucially the Treasury is missing. It needs the Minister for Disabled People to have senior minister status and power to give our equality the priority we want.

#### → Have your say

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### Technology and Internet

**LÉONIE WATSON**

Works with digital consultancy Nomensa

### Specialist Equipment

**JOHN MANDRAK**

Disability journalist and DLF helpline adviser

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**ANDY WRIGHT**

MD of Accessible Travel, specialist tour operator

### Money Management

**DAVID CLARKE**

Senior partner with Clydesdale Bank

### Access and Environment

**AGNES FLETCHER**

Disability trainer and consultant

### Property

**KATE SHEEHAN**

Occupational therapist with interest in housing

### Motoring and Transport

**HELEN SMITH**

Works with Mobilise and specialises in car matters

# Should I stay or should I go?

**Q**I've been with my partner for 11 years, though we still live in our own rented homes.

I became chronically ill ten years ago, and then became physically disabled. I now depend on sticks and mobility scooters. My partner is physically well but suffers from mental health problems, mainly long-standing depression and self-harm. I'm 40 and he's 34.

Before getting ill I was at university, which is where I met him, and was very social. I enjoyed going out with friends. Today I have no friends. I wish I did but I find socialising exhausting and I'm limited in how much I can do. My partner also doesn't have friends. He says he's not interested in anyone else.

As for my family, they live in another part of the country and we don't communicate as they've never cared about me. So, there really is no one I can talk to and I can't afford counselling.

The thing is, my partner and I don't have a physical relationship, and I feel really sad about it. When I was iller than I am now, sex was the last thing on my mind, but before getting ill, I was always very

physical, enjoyed sex and felt it was a very important part of the relationship.

When I first met my partner he was 23 and still a virgin. He has always had erection problems. We've tried lots of things but without much success. A medical check suggested he had a psychological problem. He was prescribed Viagra which helped a bit but we don't cuddle or kiss or even hold hands.

Now for all the complex stuff. I'm not attracted to him, I don't fancy him and there's no spark between us. I often think we did the wrong thing trying to have an intimate relationship and should have been just friends.

It's not just his physical appearance that I'm not attracted to: it's his personality. I think I only stay in the relationship because I don't want to be alone and feel I owe him for looking after me when I was really ill.

I also know he'd go to pieces if we split up. In fact I've tried a few times to end the relationship but we always end up back to where we were. I even had a few appointments – alone – with a Relate counsellor, which left my partner trying to get me to reveal

what we'd discussed.

He does this a lot. I think he's rather controlling on a lot of levels. I've tried talking to him about how I feel but he says he doesn't understand because that's not how he sees things.

So the question is: do I stay in a relationship I'm not happy with, just because I'm afraid to be on my own, afraid of ending up in a home somewhere, afraid of problems I have with the neighbours, and afraid of what our parting might do to my partner?

I haven't been asked out on a date for more than ten years, and I suppose I'm not attractive any more. I've been told I'm lucky to have anyone at all, given my disabilities, and that it would be difficult to find someone else, since I don't work and have no financial assets like a home of my own or a job.

It's hard not having someone to confide in. Sometimes I think this is how my partner wants things to be: this way I only get his thoughts and opinions. I just don't know.

I'm sorry this is rather long but I feel there is so much more I could say. Could you offer any advice?

Name withheld, by email



### Simon Parritt replies:

Extracting yourself from a long-term relationship, however damaging and controlling, is difficult and painful. This is especially so when the other person plays a role in your support needs.

In this case, however, you're with a man whose personality you dislike and whom you find sexually and physically unattractive. You have fallen into an abusive situation, and contrary to what you feel, you're not helping him either.

You're allowing your low self-esteem and guilt over his caring for you when you were ill to excuse his controlling dependency on you. In the end it will crush and destroy you both.

You are still young and have a life to lead. The reason you have no friends and social life is in part, I suspect, because of your partner's influence over your every thought, deed and feeling.

If, as you say, you used to be sociable and enjoyed going out with friends, what has happened? Somewhere inside, you're still that same person. Attractiveness is largely about personality and it's this that's being undermined. Surely you've sacrificed enough of your life for a relationship that's restrictive and damaging.

### Comments like 'you're lucky to have someone at all, given your disabilities' are both untrue and unhelpful

Yes, of course you're afraid to be on your own: that's a fear people often face when embarking on a new beginning, whether it's leaving home, changing jobs, moving house or divorcing. It's especially scary for many disabled people who can't just up sticks and leave. But along with the fear should come a sense of excitement and possibility: isn't it appealing not having to be responsible for a man who gives you nothing and denies you the freedom to go where and when you want for friendship and enjoyment?

Comments such as "you're lucky to have someone at all, given your disabilities" are both untrue and unhelpful. Friendships as well as intimate and sexual relationships are in the end about mutual support and sharing, not dependency and control.

If you need support and someone to talk to while you build up your courage and social skills, you could try Relate again, with the

goal of moving on in your life without this man.

Try speaking to your GP as well: some now offer a few sessions of counselling, and this may give you the strength to make changes. Voluntary counselling groups that offer low-cost counselling or even online support forums are also a start.

It also occurs to me that there's a wider aspect to your situation that many may recognise. As disabled people, we can become indebted to those whom we rely on for physical support. We can be trapped by being "looked after" emotionally

### It's always a struggle to balance our feelings of thanks to our supporters with our need for autonomy

by people who act as a dependent, unquestioning friend or partner. There's a danger of relationships becoming unequal and non-mutual. And there's a huge difference between acknowledging someone's support and love and the

feeling that you owe them your life and body. You should never have to give up your rights as an autonomous individual.

There are a few people who can't help but prey on us in those moments in our lives when we need kindness and support. Just as religious sects and cults prey upon people at vulnerable times in their lives, so can people we're in a relationship with.

For a disabled person it's always a struggle to balance our feelings of thanks to our supporters and enablers with our own sense of identity as autonomous individuals.

As we saw in the feature "Taking Back our Lives" (*Disability Now*, April 2010), there must be many more disabled people who experience physical abuse in their relationships than we think. But, how many more are restricted and imprisoned by the subtle emotional blackmail of those who care for us? Do they not slowly damage our independence, self-esteem and autonomy out of a need to fill the gaps in their own lives, unaware of the price we pay?

#### → If you have a question for our panel

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# pete's place

## Three pointers



As the new Government takes office, **Peter White** suggests three ways that disabled people's lives could be helped

**A** harsh verdict was delivered after a radio discussion I chaired in the run-up to the election in May.

Broadly, listeners felt that the representatives of the three major parties who took part didn't care about disabled people's problems. (My own view was they also didn't know about them.)

No one could say, for example, how jobs would be found for the million or so disabled people the parties say they want to get into employment; or why a fit 66-year-old should get the winter fuel allowance while someone under 60 with circulatory problems couldn't (to be fair, the LibDems did have a bit of an answer to this one); or why pensioners should have their carers' allowance removed, even though carers' responsibilities were likely to increase.

So, in a spirit of helpfulness, I'd like to offer three policies to genuinely help disabled people in this country, even if they're unlikely to be acted upon.

First, I'd like to see an uncoupling of the link made

by the parties between reducing the benefits bill and "helping" disabled people back into work. It's a spurious and pernicious link, based on a blip in history when, at a time of severe unemployment, some people were signed on to what was then Invalidity Benefit rather than put on the dole. If the connection really held good, the numbers on benefits would have declined years

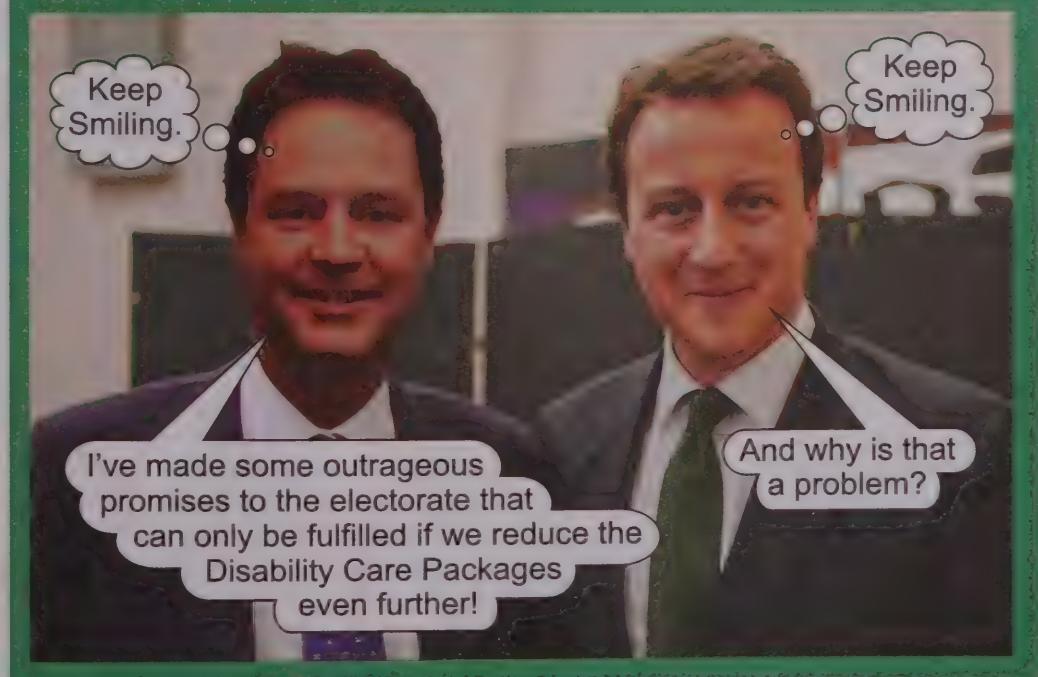
ago, as the people involved – usually in their late 40s or 50s – reached retirement age. The fact it hasn't done suggests the disabilities claimed for are largely genuine. In my experience, disabled people do want to work, but it's barbarous and economic nonsense to drive them into "non-jobs" with threats of benefit removal. (Oh, and if the benefits paid to such people could actually support a decent lifestyle, that would be better still.)

Next, I'd like the laws on providing accessible equipment extended to manufacturers. At the moment we have the daft situation where retailers are expected to make their services

accessible while selling kit that's unusable. If manufacturers (and designers, for that matter) were required to produce things that could actually be used by disabled people from the start rather than having to have them adapted, it would make far more sense and end up being good for everyone, since design that takes the needs of disabled people into account helps everyone!

Finally, all disabled people should be provided with a broadband connection and adequate equipment if they can't afford it, regardless of whether they work or not. Wasn't New Labour promising something along those lines 13 years ago?

### ed cetera



# guestcolumn

## Social work: are we in at the death



With high profile system failures such as the Baby Peter case, focus on social work provision has switched firmly to children. **Professor Peter Beresford** asks whether this is a good or a bad thing for disabled people

**D**isability Now columnist and pioneer, disability academic and campaigner Mike Oliver (*pictured*), wrote a damning indictment of social work with disabled people. In the new edition of his key text, *Understanding Disability*, he concludes "we can probably now announce the death of social work at least in relation to its involvement in the lives of disabled people" (p51). He sees social work as doomed because of its failure to adopt the social model of disability and connect with the rights and needs of disabled people.

At a time when policies tend to creak along rather than change dramatically, some might think Mike's guilty of exaggeration and over-simplification. As someone with experience on the receiving end of social work, as a social work educator and with a belief in the fundamental value of social work, I would say we ignore his words at our peril.

Social work is undergoing radical review. Following the tragic death of Baby Peter a social work task



force was established to recommend reform. Since then a social work reform board has been set up with cross-party support to carry this through. Attention predictably has tended to focus on social work with children and families. That's become code for child protection work as policymakers have increasingly shaped and narrowed the role of social workers. Their cure-all is the setting up of a College of Social Work – although how this is to change everything remains unclear.

Adult social work meanwhile remains on the periphery, for all the highly evidenced cases of

**Their cure-all is the setting up of a College of Social Work – although how this is to change everything remains unclear**

comparable abuse, neglect and hate crime that can be set alongside examples against children. But the truth is that those people government chooses to see as "vulnerable adults", who the rest of us might see as people whose rights are

regularly put at risk in a discriminatory society, don't carry the same political, media or popular priority as children. Add to this that the push for personalisation and individual budgets has been used as a cost-saving measure to cut back on qualified social workers and the scale of the threat becomes clear. Good social workers offer disabled people two key things. First is support that is based on a social rather than medicalised approach. Second, are opportunities for careers themselves as social workers, offering prospective service users the added value of first-hand experiential knowledge.

Government determination to convert adult social work into mechanistic care management has undoubtedly undermined its credibility, converting it from a source of support to a rationing system. But if there is to be any prospect of support truly being based on the values of independent living and the social model, then we all need to be part of the fight-back to save and renew adult social work.

### → Have your say

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# upclose & personal

## When the joke's on me

Comedian Frankie Boyle was recently in the news for making cruel jokes about people with Down's syndrome. He'd been challenged at one of his shows by a mum of a young daughter with the condition, angry and upset by his remarks. **Victoria Wright** knows the feeling

**S**everal years ago after appearing in a BBC documentary about facial disfigurement, I found out from a friend that Ricky Gervais and Stephen Merchant (co-creators of *The Office* and *Extras*) and Karl Pilkington had made jokes about my face on their Xfm radio show. Pilkington had described me as "the woman with the big head, like Bo' Selecta!" after the Channel 4 show featuring a character with a large chin and bulging eyes. He'd joked it was hard to remember that people with facial disfigurements are human "because they don't look human". There was much laughter from Gervais and Merchant along with jokes about "midgets" and the Elephant Man.

I rang XFM demanding a recording of the show, which I received along with a letter from Pilkington inviting me to come on the show and "pretend" to tell him off. After listening to the recording I was overcome with shock. Having someone shout abuse at me in the



Clockwise from top: Victoria Wright, Frankie Boyle and Ricky Gervais

street is one thing – at least I can choose to ignore them or wallop them with my handbag. But to be humiliated on radio for thousands of people to hear was something else. I felt bruised, angry and powerless.

I emailed a complaint to the managing director of

Xfm who wrote back, saying he'd spoken to them, and apologised for the distress they had caused me. He gave me his "absolute assurance that such comments will not be broadcast on the station again". I didn't take my complaint any further as

I thought that would be the end of the matter. But over the years, every time someone shouted "Oi Bo Selecta!" at me in the street, I was left wondering if they'd heard the Xfm show.

Only recently did I learn that a couple of months after the *Bo' Selecta!* episode, Merchant had joked on the show that it was great I hadn't complained(!) and that I was a bigger person than Pilkington "at least

**To be humiliated on radio for thousands of people to hear was something else. I felt bruised, angry and powerless**

head wise". Gervais had even asked Pilkington where I would come in his "freak of the year" list. So much for absolute assurances.

People like Boyle, Gervais, Merchant and Pilkington might think they're just having a laugh. But for those of us on the receiving end of their jokes, it really isn't a laughing matter.



# Everything including the kitchen sink

If you're disabled, image can't always be everything, there are pesky practicalities to consider too. But **Lara Masters** discovers that when it comes to kitchens, it is possible to have both style and substance

I am currently redecorating my house which is reinforcing my acute sense of aesthetics – I feel actual joy seeing old yellowing walls transformed into white and have discovered I can quite happily watch paint dry. Yet my physical limitations force me to have certain articles in my home that are skin-crawlingly ugly like a hulking grey shower-chair and an electric bed made from "wood effect" laminate.

My kitchen on the other hand looks good but is pretty inaccessible as I didn't want every room in my home to be tainted by nasty looking furniture, so meeting Adam Thomas (*pictured right, right*), a wheelchair-user destined to design stylish and accessible kitchens, was a revelation.

"In 1980, I left school at 16 and signed on. In those days, you had to take one of your first three job offers or you lost your benefit. Number three for me was with kitchen company Design Matters. I turned up in my leather jacket, on my motorbike, no portfolio, but I'd always loved art and design, so when I was asked to draw a plan in 3-D I could do a pretty good job."

"A year later, I had a road traffic accident which triggered my



involvement in campaigning for civil rights. I met lots of disabled people and when I saw their homes I often thought: 'There's so much more you could do in your own kitchen if it was better designed.'

In the early 1990s Adam left work to focus on campaigning and was heavily involved in helping shape our Disability Discrimination Act but, almost a decade later, he got back into the kitchen.

"At the end of the 1990s, I thought I'd combine my personal and

professional experience to make accessible kitchens for disabled people at Design Matters. My designs are fine-tuned to the needs of the individual. I've never met anyone who couldn't do more to cook for themselves, make tea for their friends and family, whatever, with a more appropriate kitchen. Often, storage is out of reach, ovens and hobs are dangerous, fridges and dishwashers are set at the wrong height. The right kitchen can be liberating, maximise independence and allow someone to have more control over what they eat and drink."

To date, Adam has over 500 very swanky looking accessible kitchens under his belt (or apron) and I was surprised to learn they are often built with council funding.

"Obviously local authorities are up against it financially but a cheap unsafe kitchen that falls to pieces after a year, particularly with the heavier wear and tear from a wheelchair banging against it, is a waste of public money. Often we're called in after someone's had a cheap kitchen done by another company and it's all gone wrong. I've seen so many chipboard kitchens that are splintering and

falling apart because they just aren't up to the job.

"That's one of the reasons we created the Access Matters range of flexible and affordable kitchen furniture. We work with some fantastic finishes which can transform the look of anyone's kitchen. Using the latest, cutting edge materials costs no more than the usual boring stuff – it's convincing the grants offices that's the problem, especially when one penpusher commented: 'He can't have this kitchen; it's nicer than mine.'"

Seeing the photos of Adam's creations has also given me kitchen-envy; suddenly mine looks rather inadequate and a bit pointless even with its beautifully white walls - but it's not just Adam's kitchens that are impressive - he's one of those rare people who live



by their principles and are pro-active.

"Access has improved hugely during my lifetime but it still gets to me that I can't get into some of my non-disabled friends' houses. I'm involved with the Q Well Being development of fully accessible luxury apartments in Cyprus, which includes a heated pool designed by Dame Tanni Grey-Thompson. I'm also part of the

Habinteg Lifetime Homes campaign which if enforced will make a huge difference to disabled people's lives."

Looking at Adam's past campaigning work and current projects, it's clear he's an exemplary addition to the disabled community, both with his pioneering inclusive designs and his idealism and diligence in helping raise standards to make life much better and fairer for disabled people. ■

## Information

Find out more about Adam Thomas's work at:

Design Matters –  
[dmkbb.co.uk/accessible-kitchens](http://dmkbb.co.uk/accessible-kitchens)  
Habinteg – [www.habinteg.org.uk](http://www.habinteg.org.uk)  
Q Well Being – [qwellbeing.com](http://qwellbeing.com)

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# Mayan days

## Mexico's Caribbean Coast



Before the recent oil spill disaster, **Penny Batchelor** had close encounters with ancient Mayan culture and crocodiles when she holidayed on the Yucatán peninsula, part of Mexico's Caribbean coast

**I**t was the Mayan idea of a football match, except only the elite were allowed to spectate in the ball court. The Ronaldos and Beckhams of the day competed in two teams to keep the rubber ball in the air using only their hips, thighs and arms.

Kicking with feet or throwing with hands was banned.

A team won by pitching the ball through a small hoop high up in the air at the side of the court. The jury is still out on whether it was the winners or the losers who got the booby prize:

some scholars believe that the winners won the privilege of being sacrificed to the gods!

Today, the only actions seen at the ball court at Coba, on the Yucatán peninsula in the east of Mexico, are by tourists taking photographs. A prime



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photo opportunity is a stone carving of a kneeling man with a head of a sacrificial victim on his back.

The ruins are in an excavated part of the jungle, with temples still being reclaimed by archaeologists from nature. It's a long four kilometre walk round but I took the easy way out, hiring one of the many cyclists to ferry me round in comfort on the front seat of his tricycle.



Penny on a tricycle at Coba

We passed the tallest climbable pyramid in the state, at 137 feet, with visitors clinging on to a rope struggling to get back down. "Going up is easy" our guide had warned. "Coming back down is the hard part". It was far more fun to watch than do.

Coba's remains are one of many ancient ruins scattered across the state, dating from before the Spanish colonisation of the country.

The Yucatán is Maya territory. The Mayan people, whose descendants still live in the region today, reached the pinnacle of their empire around 900AD. Their cities were not only in Mexico but also in Guatemala, Honduras and El Salvador.

I stayed in the small resort of Tulum,

### Did you know?

There are 103 known mammal species in Sian Ka'an and 336 bird species.

**In Mexico August to October is the season for tropical storms, but outside of that period you're almost guaranteed balmy sunshine**

an hour and a half away from Cancun, the area's main tourism centre. Tulum's hotels hug the Caribbean coast and most have access to their own stretch of beach, with lapping waves of surprisingly warm water. Indeed, the sea was warmer than the hotel's pool! Lying on a beach lounger between sightseeing trips was a great treat. In Mexico August to October is the season for tropical storms, but outside of that period you're almost guaranteed balmy sunshine.

Mexico as a country doesn't have the same high standard of disability access as its northern cousin the USA, but provision varies. International hotels, such as Dreams, where I





Above: Crocodile at Sian Ka'an; below: Tulum ruins



stayed, tend to cater for all their clients. Being newly built they have the ramps and facilities you would expect, with nothing being too much trouble. They are, however, much more expensive than locally run, smaller hotels and you do feel that you could be staying anywhere in the world. Ask before you book your accommodation so you know what to expect.

A short taxi ride from the resort's hotels is the original site of Tulum – the Mayan ruins. In the Mayan language Tulum means fence or wall.

The first Spanish explorer on record to see the fort, surrounded by the coast on one side and walls on the three others, thought it more entrancing than Seville. The town was an important trading port in the Mayan civilization.

Whilst the ruins at Coba (a UK health and safety manager's nightmare!) sprawl through the jungle, Tulum is a much smaller and tidier site, with set paths to follow and climbing prohibited. There's even a wheelchair ramp, although its steep gradient makes it only for the more adventurous.

### Did you know?

Mexico is the most populated Spanish speaking country in the world.

The buildings at Tulum include the Temple of the Frescoes and El Castillo (the castle), which is the tallest building in the site. Wandering round the paths of the 800-year-old town I got a glimpse of what life would have been like for the original inhabitants. Only the stone platforms remain of where their houses would have been – the wooden structures and their gardens where they

**In the Mayan language Tulum means fence or wall. The first Spanish explorer on record to see the fort, surrounded by the coast on one side and walls on the three others, thought it more entrancing than Seville**

cultivated their crops have long since gone. Yet the structure and layout of their town remains.

The site's exit has a few steep steps. I found it easier to go back to the ramp and leave via the entrance. From the car park there's a short walk to the site's entrance but there's a tractor pulling a road train on hand to take those who prefer to ride instead. I received both a free ride and free entrance to the ruins – it's worth asking for disability discounts.

Nearby Tulum and all over the Yucatán peninsula are cenotes, areas where the top rock has collapsed to reveal a swimmable-in sinkhole underneath. The Maya believed they



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## Cenote cave: the Maya believed they were sacred entrances to the underworld

### Did you know?

The Mayan calendar had 260 days.

were sacred entrances to the underworld. Today they are a great way to cool down after a long, hot day's sightseeing, although being natural and surrounded by rock they are not that easy to clamber into.

A 45-minute taxi ride south of Tulum is the Sian Ka'an biosphere reserve, a sustainable development and ecotourism area. Sian Ka'an is a UNESCO World Heritage Site and has 1.3 million acres of land by the coast. From mangroves, savannahs and tropical forests there's a multitude of habitats to explore and wildlife to spot. Entrance to the reserve costs four US dollars per person.

We headed for the visitor centre and chose to go on an hour's boat tour to

explore a small part of the reserve. Sadly the manatees living in the water didn't come out to play but, as we motored past yet another Mayan ruin, we did spot a crocodile lazing on the shoreline and many birds going about their daily business. This, away from the crowds of tourists in the resorts, was another side of Mexico: the natural habitat that has existed for thousands of years.

Sian Ka'an means "where the sky is born" in the Mayan language and as we sped out to where the lagoon meets the ocean and the blue sky I could see where that name came from.

That calm and serenity is the opposite of everyday lively Mexican life. Back in the real world, in the scrum at the airport to fly back home, I was reminded of the fierceness of the ball court. Surrounded by lots of pushing and

shoving to check in and get through customs I nearly lost my head: not literally, but my temper! ■

### Don't miss:

- Chocolate fans shouldn't miss tasting chicken mole – chicken in a delicious, spicy sauce with a hint of chocolate.
- A traditional Mexican mariachi music band with trumpets and guitars.
- Sunrise or sunset over the shore and ruins of Tulum.

### How to get there:

Penny travelled with Virgin Holidays from London Heathrow to Cancun in Mexico flying via Miami. Other airlines also fly to the city, including charter flights on package holiday tours.



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# tried & tested

## Monster mashing

Taking the mashing out of mash, Ian Macrae checks out a new potato ricer

**F**or mash, get "Smash", said the now almost retro-chic TV ad for the Cadbury's instant collation. And the way in which we earth-beings treated the noble spud had the little aliens rocking with metallic laughter.

But let's face it, if what you want is really smooth, tasty, totally lump-free, buttery mashed potato to bulk out and add a new dimension to a classic dish, as well as soak up that delicious gravy, the answer can never come out of a packet.

Having said that, up till now, producing said silky smooth mash may not always be the easiest or most accessible of kitchen activities.

You could blitz it up in a food processor if you have one, but the risk of over-blitzing is considerable and produces soggy glutinous results.

Mechanically, there are two basic ways of mashing, both of which require considerable arm and hand strength.

The first is your standard issue masher, a plate with holes in it stuck on the

end of a vertical handle. You use the implement like a plunger to pulverise your boiled potatoes. But reducing to a consistently smooth consistency takes time, effort and patience.

The other way is to use a potato ricer.

There are several varieties of these around. My old one came from IKEA and like many of their products, price and basic functionality meant compromise on style and finish. It was an ugly, charmless brute and using it again required a lot of arm and hand strength.

The other type is based on the same sort of design as an old fashioned garlic press, and it's this kind which has been given an



the gadget much easier to use.

My only quibble would be that the underside of the lower arm which sits across a bowl as you put the potato into the ricer is rounded and therefore inclined to wobble. It would be better flat so that it sat with greater stability.

But for smoothness, both of operation and of the mash it produces, this gets top marks.

### Recipe suggestion

- Creamy garlic mash
- Cut 6 to 8 potatoes into pieces and boil for around 12 minutes.
- Meanwhile peel 5 cloves of garlic, melt some butter in a pan and fry the garlic cloves whole for 3 minutes.
- Strain the potatoes and put them and the garlic through a ricer keeping the butter
- Mix the butter into the mash stirring thoroughly and add a good splodge of double cream.
- Stir thoroughly.
- Good with any meat that's served with sauce or gravy.

### Information

Chef'n Potato Ricer, ref 14028, £29.99  
Order online: [www.lakeland.co.uk](http://www.lakeland.co.uk)  
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# helen smith



## The case for a fuel rebate

In Ireland, disabled motorists who rely entirely on their vehicle get a rebate on the cost of fuel. **Helen Smith** wonders whether it's time the United Kingdom followed suit



**T**he title of the letter that arrived on my desk recently was "Is this progress?" In it, a Mr Rogers explained how times have changed and now, instead of being issued with blue three-wheeled invalid carriages, disabled people can now choose practically whatever car they like from the

Mobility scheme.

Although full of praise for the scheme, Mr Rogers then posed this question: "This year my Incapacity Benefit has been frozen, my total raise in income is £1.60 while the cost of fuel is being allowed to skyrocket. For those of us unable to earn and solely dependent on benefits, it looks like it

will be back to a one-seat electric scooter with limited mileage. Is this progress?"

Although I believe that a lot of progress has been made to improve the mobility of disabled people I fully sympathise with Mr Rogers's view. When we have to leave our vehicles in the garage or even give them up because we can't

afford to run them, something needs to be done to help us fund the fuel.

One suggestion comes from Alan Lewin who is a motorised wheelchair-user. He writes: "Can we pressure whoever is likely to be the new Chancellor that there is a case to be made to grant us a discount on fuel tax when totally dependent for

survival on the car? My hefty motorised wheelchair won't be carried by taxis or buses."

This is in fact exactly what happens in the Republic of Ireland, where qualifying disabled drivers and passengers are able to apply for a repayment of excise duty on fuel used in the vehicle they either drive or travel in. The maximum amount of fuel that can be claimed is 600 gallons or 2,728 litres per year.

This rebate would make an enormous difference to people who have no option

**When we have to leave our vehicles in the garage or even give them up because we can't afford to run them something needs to be done to help people fund their fuel**

but use their own vehicle.

The response from the British Government has been that disabled people get Disability Living

Allowance to cover the extra costs of living with a disability, but when this benefit is used to pay for the monthly Motability instalments there is nothing left to pay for fuel.

Obviously, disability benefits are different from one country to another but when I spoke to the Irish Wheelchair Association they confirmed that as well as being able to claim back fuel duty disabled people also receive a disability benefit.

With fuel prices showing no sign of dropping, I think

the time has come for the new Government to review how disabled people are supported and in particular their mobility needs. It's all well and good providing disabled people with a free bus pass but this is next to useless for a significant number of disabled people who can't use the bus. The fact that a fuel tax repayment system is already being used in Ireland shows that it is tried and tested and is going some way to help disabled people who are reliant on their vehicles.



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By Paul Carter

"Our job as an organisation is to ensure that those who provide or make policy with regards to physical activity take on the responsibility to include disabled people," explains Stewart.

It's this philosophy of inclusion that underpins much of Interactive's work, and marks a move away from providing services in its former guise as the London Sports Forum for Disabled People.

"We made the decision when we shifted our strategy four or five years ago that, if we carried on providing services, yes, we would carry on supporting a small group of people, but we would never actually change that wider spectrum.

"Using an example of visually impaired children – we were benefiting maybe 30 children, usually the same 30, each summer. And those 30 children really benefited from it, and the parents really appreciated it, but I think the real sea change for us came when we looked at Sport England's Active People survey in 2006 and for the first time it showed that essentially 75 per cent of disabled people in London don't do any sport or physical activity.

"That means that there are about 1.2 million disabled people in London who aren't doing sport. Actually, us helping 30, and

## Claiming the right to be active

**Paul Carter speaks to Stewart Lucas, chief executive of Interactive, formerly the London Sports Forum for Disabled People to discuss the reasons behind the organisation's rebrand, and the issues facing disabled people wishing to get involved in sport in London and beyond**

in some cases the same 30, how is that really essentially increasing the participation levels of disabled people in London?

"We realised that by providing very good, quality provision, we were actually allowing the mainstream off the hook."

Stewart explains that there is something of a dichotomy at present in disability sports provision across the country that organisations such as Interactive are working to bridge.

On the one hand, many sport providers are failing to provide disabled people with accessible, inclusive services; while on the other, take-up among the disability community is not large enough to convince providers there is a market.

He says: "There is a real issue in that mainstream sports providers see themselves as just that – mainstream sports providers. They don't see themselves as a disability provider because they don't see disabled people as being part of the mainstream. And almost by us going and providing separate activities, we were in many ways almost allowing that to continue.

"For us the concept is all very much about how do we sell being active as a viable lifestyle choice for disabled people? Saying, you have a



**Stewart Lucas**

right to be active. You have a right to ask to be active. We're very good about shouting about employment, we're very good about shouting about our rights to jobs, our rights to transport, our rights to culture, but I don't think we're as good at shouting about our rights to be active."

However, Stewart is keen to stress that the situation is already much better than even five or six years ago, and matters are continuing to improve.

So with that in mind, where can disabled people who are interested in getting involved in sport or physical activity, even at a very low-key level, go to for information?

"The best place in London to contact at the moment is us. That's the first point of call. If it's outside of London, the best place to contact is the English Federation of Disability Sport and go to their website.

"Or, just go and do activity yourself, ring up your local club. I think that's almost

the other side of it – I would say where we as disabled people have got to take responsibility is by saying 'I want to be active. I'm not going to sit here and wait for someone to do it unto me, I'm going to go and basically do it myself. I'm going to go to my local club.'

"If you go to your local club and they say 'oh we can't provide for you', talk to us. Talk to EFDS. We'll either be able to tell you a club that can, or we'll be able to talk to that club so that they can provide for you. But that local club is not going to see a disabled person as a market until that disabled person is standing there and saying 'I want to take part'.

"If 200,000 people suddenly rang up their local clubs tomorrow, they'd suddenly sit up and take notice, because suddenly there's a market there."

One scheme which has the potential to greatly improve disabled people's ability to find accessible gyms is the introduction of a new 'kitemark' scheme called the Inclusive Fitness Initiative (IFI).

Stewart explains: "It's an accreditation that gyms and providers can get which says 'this gym is inclusive' and that is defined by means of four separate criteria. There's physical access, there's equipment,

there's training and then there is outreach and marketing. And they have to pass all four of those.

"It's also about having the entire staff trained in disability equality. It's all well and good having your fitness instructor have level 2 training disabled people, but if your receptionist doesn't understand it, you're not going to get past the front desk."

Work by organisations such as Interactive is undoubtedly making great strides in opening up the fields of sport and physical activity to disabled people.

"The absolutely crucial thing for me is that providing sport to disabled people isn't something charitable", says Stewart.

"It isn't a good cause, it isn't a 'nice thing to do', it's pure and simple, route 101 equality. After all, why should our involvement be seen as having less worth?"

- To find your nearest IFI Mark Accredited Facility, visit [inclusivefitness.org](http://inclusivefitness.org)



**inclusive fitness accredited site**

# entertainmentnow

## FILM



disability. There are a couple of references, someone identifies him as "that short guy", but even when the entire cast is pissed off with him, they seem too afraid to insult him. It isn't believable. Let's face it: it is hard not to point out unusual characteristics about someone when you are angry and want to hurt them.

As a result it's all rather stiffly acted; the other characters are devoid of any emotional attachment to Frank despite the fact that he's done something extremely hurtful.

Sometimes, just sometimes, it is okay to laugh at disability. This is a toilet humour film, surely it is begging for a couple of short gags? For example, when Frank is dropped into the coffin alongside the dead body, it's quite funny that because of his height he looks as though he's doing something unquestionably rude to his former lover. But all we get are uncomfortable, robotic stares from Rock, Lawrence and co. who, at this point, are probably wondering why on earth they thought this film might be a good idea.

**Cathy Reay**

- *Death at a Funeral* is in cinemas on 4 June via Sony Pictures. Duration: 92 min.

## ***Death at a Funeral? It was more like death in the audience.***

You have to wonder what was running through Neil LaBute's mind when he decided to direct a remake of an at best mediocre British film, which was only released three years ago. Alas, here we are with *Death at a Funeral 2.0*: the really boring American version.

Unusually for a remake, short-statured actor Peter Dinklage reprises his role as Frank, an unexpected funeral guest with a mysterious connection to the deceased. When Frank confesses the real reason he

is attending to Aaron and Ryan Barnes, sons of the dead man played by Chris Rock and Martin Lawrence respectively, and tries to bribe them for money, all hell breaks loose.

While the original worked reasonably well with its understated gags and subtle irony, the Yanks have copied and then shot bullets through each joke, exaggerating and adding unnecessary bluntness to a script that was already pretty paint-by-numbers. In doing so they have created a film that is far more cringe-worthy, overacted and, as a result, devoid of

any hilarity.

It isn't hard to see why Dinklage accepted the same role again; this is arguably the most name-droppable cast he's ever been paid to star alongside, though *Death at a Funeral* is a career low for most of them (aside from James Marsden, who plays a hilarious 'accidental' pill-popper). Though not given much screen time, Dinklage does act his part reasonably well, in fact it is the rest of the cast that are the problem.

Like the original, for all its tongue-in-cheek gags, the American film awkwardly dances around Frank's

## THEATRE

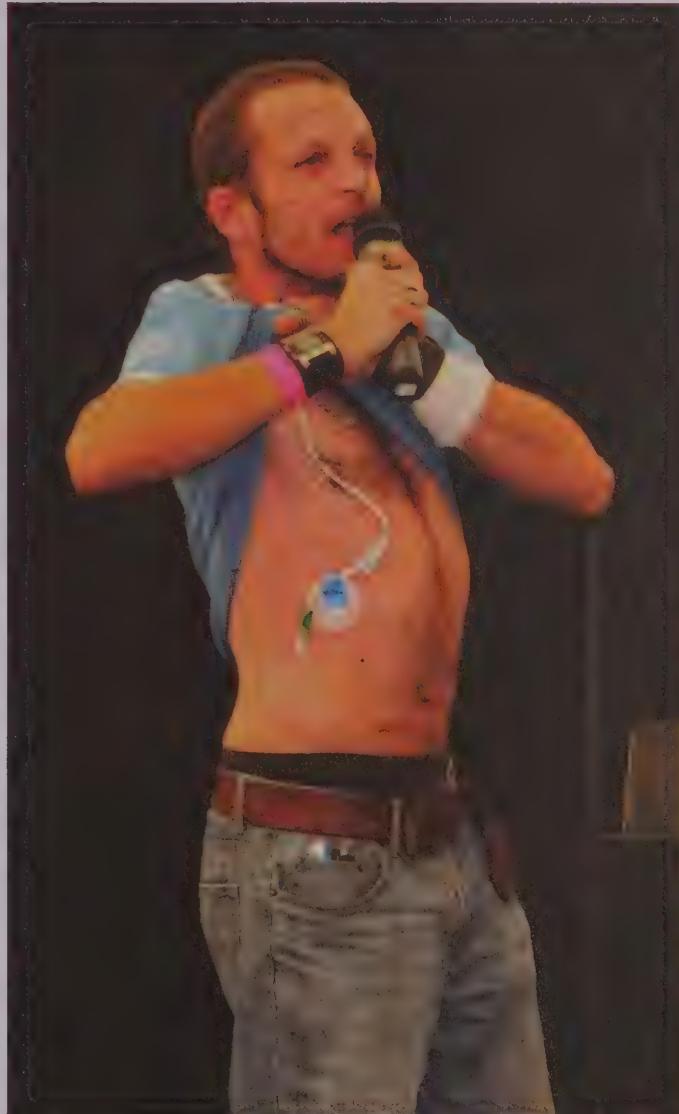
**Cracking Up!**

Developed by NHS Surrey, *Cracking Up!* is a variety night based on the experiences of people with mental health conditions. Only one of the performers is disabled but it still feels like the contributors have been empowered, getting their stories across, rather than being exploited for laughs or patronised.

Edgy jokes from the cheeky compere, John Ryan, link sketches performed by actors, poetry, and both stand up comedy and raw personal revelations from Gareth Berliner (pictured). The format felt familiar; it reminded me of Catholic youth weekends I used to go on in Derry where the audience would be laughing at a skit one minute and crying at a sad story the next. It's a heady mix if you want to slip in a worthy statistic, whether that is that one in four people will have a mental health problem or that there are three people in the one holy trinity.

Cunningly manipulative! And suspiciously enough, John Ryan did mention his Irish Catholic roots a few times.

In the first half Gareth Berliner performed a well-crafted stand-up routine about his Crohn's disease. I'd first heard this material



KELLY MULLAN

at last year's Liberty, the disability arts festival in London and though it's funny, I was wondering what it had to do with mental health. All became clear in the second half when Berliner told the blackly comic tale of how his physical illness led to a descent into depression and

a failed suicide attempt before he finally told his family and asked for help.

In the most simple and most effective part of the show, John Ryan got a

hapless volunteer from the audience to attempt to juggle as he threw more balls at him. This funny scene has stuck in my mind and helps me take a lighter view of making a balls of things.

*Cracking Up!* producer, Maya Twardzicki says: "The scripts of both the sketches and the comedians were informed by focus group discussions with about 60 men from different demographic groups – two of the sessions were held with men with experience of mental ill health at mental health voluntary organisations.

"The poet Tom Iddon who wrote the Stigma poem, read by John Ryan, has direct experience of mental ill health. In previous shows we have also used another comedian and musician who also have direct experience.

"The artwork shown during the interval was all created by people with experience of mental ill health at Art Matters in Surrey."

**Kelly Mullan**

- For further information on *Cracking Up!* contact Maya Twardzicki on m.twardzicki@nhs.net

**→ Up-to-the-minute listings**

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# webwatch

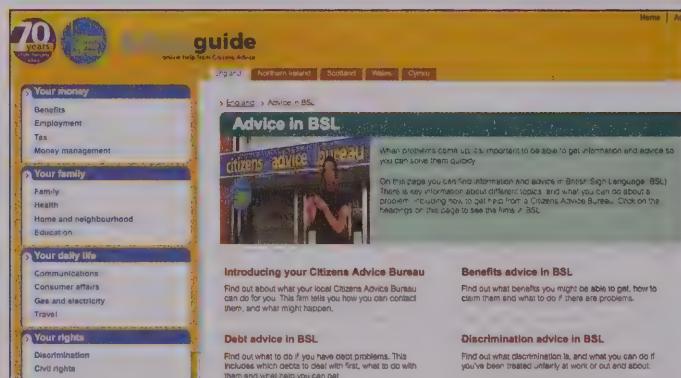
## CAB puts BSL online

In a move to expand its accessible services, Citizens Advice has just gone live with a British Sign Language service for deaf customers. **Sunil Peck** reports

**A**ccess for deaf people to the legal and financial advice provided by the Citizens Advice Bureau (CAB) has been widened with five online films in British Sign Language (BSL) produced by the charity.

There's an introductory film with information on arranging an appointment with an adviser, along with the kind of information you should take with you. The four other films contain advice on clearing debt, the social security benefits you can claim, what you can do if you've been discriminated against and employment rights.

Ernesto Bueno Del Carpio (*pictured below*) is deaf and advises clients at Citizens Advice in Wolverhampton. He acted as a consultant in the



**This would enable us to have full access to information and make informed choices**

making of the films and thinks that other BSL users will find the web resource useful for resolving their legal and financial issues.

He said: "Very often deaf people are too intimidated to go to a bureau because they fear they will have communication problems. While a BSL video does not provide instant advice, it can help start the client in the right direction."

Asif Iqbal (*pictured right*), Media and Project Manager at Deaf Parenting UK and a BSL user, welcomed the

online films and said that they would cut out the need for BSL users to rely on interpreters.

He said: "It is fantastic to have the information and advice on debt, employment rights, anti-discrimination and benefits in BSL. This would enable us to have full access to information and make informed choices. We have



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- phone us 020 7619 7323

had to reply on support from other people in BSL to explain the information from English to BSL but having a BSL version on the Citizens Advice website means deaf people are able to understand which information and advice to use quickly."

As part of its plan to widen access for deaf people, Citizens Advice has a service where BSL users can communicate with advisers in BSL either in their local branch or via web cameras with advisers in other parts of the country.

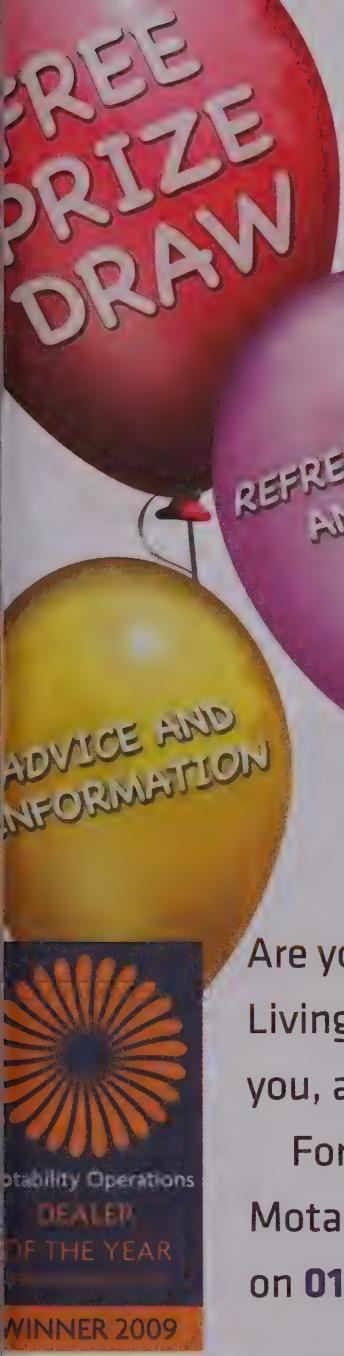
Citizens Advice in Scotland says that they have no plans to introduce online films in BSL but the charity's partner in Northern Ireland says that it is being considered there.

Citizens Advice will also be distributing DVDs of the films to all bureaux in England and Wales which would be available for deaf clients to watch.

There are also transcripts of each film which can be downloaded from the website.

- To watch the films, go to [www.adviceguide.org.uk/index/bsl.htm](http://www.adviceguide.org.uk/index/bsl.htm)





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# Hiring and firing: the employer's story



When you need support with personal care or any other aspect of your life, finding the right person to assist you is one of the most important things you can do. There are lots of things to consider, says **June Craven**

**A** personal assistant generally needs to be someone who is reliable, that will be there when you need them to be. They need to be able to help you with whatever you need but at the same time they need to know when to step back and give you space and much needed privacy, which can sometimes seem a bit elusive when you need support with some of the most intimate areas of your life.

In my case that's why I always look for people who I have something in common with, some shared interests, or even in some cases a shared ambition. In

a nutshell I try and look for people who I would have been friends with if we had met under different circumstances. Some people prefer to keep as much distance between themselves and their PAs as possible. If you feel that way you will probably find a different way of working, but to me trying to create distance where there naturally isn't much has never really felt like a good idea.

This in itself can lead to problems. If you try too hard to be friends with a new assistant then there is a risk they forget important aspects of the employee/employer

relationship such as the aforementioned reliability. This is where the balancing act comes in, balancing friendship so that you feel comfortable around someone you are probably going to be spending a lot of time with, alongside ensuring they still have respect for you as an employer.

My initiation into employing people directly seems funny to look back on now, but at the time it felt like the worst possible scenario. I had advertised through a newspaper with a large circulation but somehow still only managed to get two responses, so obviously

I interviewed both of them. I employed the best of them – the only one I could actually communicate with and this was my first mistake. From there it got progressively worse.

For reasons of religion she refused to assist me when I went out, even though that was one of the things that had been clearly discussed during the interview. Then I found out that she was squeamish when it came to poo, which she insisted on calling faeces even when I asked her not to because it made me feel like a lab rat. This must have gone on for a week or two during which time I found out the real meaning of the saying "ants

in your pants", not an experience which I would wish on anyone especially if they have to sit on their arse all day!

In the long run this all meant that I was not only going to have my first experience of employing somebody, I was also going to have to fire them as well. I have never been so nervous, even though I had asked her to come in specially and I think we both knew what was going to happen. I had typed up a letter that was clear and firm but as nicely worded as

possible. That didn't stop me feeling sick as I opened the door to where she was

**She was squeamish when it came to poo, which she insisted on calling faeces even when I asked her not to because it made me feel like a lab rat**

waiting. I forced myself to say something similar to what I had written in the

letter and then practically bolted back out of the room. Once I had dealt with it I was almost glad that it had happened. It meant that I had dealt with most of the major things that could be thrown at me at least once and, let's face it, after that things really could only get better.

Being somebody's boss does come with a lot of responsibility. One way to avoid the majority of this is to get your assistants through an agency. While this might be a good solution for some people I

think employing people directly gives you a lot more control. There are other benefits too, like flexibility. It's a lot easier to discuss and work around changes in your lifestyle when there is no third party to go through. In my experience it has given me a lot more freedom; allowed me to travel when I wanted to. Yes, sometimes it can seem like it's more stressful being an employer, but to me the feeling of knowing that you are running your own life is well worth the extra work that it brings.

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Sally, Michelle's mum



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2010(10) Ford Galaxy 1.8 Dci Edge, 5sp, A/C, Low Floor, 5 seats, NEW  
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## EVENT



**This summer the Norfolk Coalition of Disabled People will be celebrating and exploring the experiences and aspirations of disabled people with Disability Pride.**

**Disability Pride will see a whole day of activities, performances and celebrations at The Forum in Norwich, Norfolk on 5th June 2010.**

Disability Pride is about celebrating disabled people's identity and community. It is about showcasing talent, achievements and successes in arts, culture, sports and music.

The day's performances will include:

- International Musician Johnny Crescendo
- Poetry from renowned artists including Peter Street and the SHAPE UK Poetry Exhibition
- Visual artists such as Tanya Raabe
- Singing from Norfolk's renowned Sing Your Heart Out group and Molly Barrett
- Performance artists including Caroline Parker and D 4 Dance
- Sporting events from a number of local teams.

Disability Pride is for anyone and everyone who considers themselves to be a disabled person; be it through mental health, physical and sensory impairments, learning disability or any other kind of long term condition.

As a prelude to the main Disability Pride event, on Saturday 5th June, a Benefit evening of entertainment will be held at the Norwich Arts Centre on Friday 4th June.

The event will be headlined by international musician Johnny Crescendo and include a wide range of local bands and performers.

For more information regarding Disability Pride and the Benefit Gig, please visit [www.ncodp.org.uk/disabilitypride](http://www.ncodp.org.uk/disabilitypride) or contact Ann Young: email ann.young@ncodp.org.uk or tel 01508 491218.



Being the Boss is a user led not-for-profit organisation which supports disabled employers to employ their own Personal Assistants, carers or support workers. We are just one year old and we have already attracted a lot of interest not only from disabled people but from Local Authorities, other user led organisations, centres for independent living and various charities.

We have formed an Association of Disabled Employers who receive a newsletter quarterly and an Employers Handbook. This handbook is available in standard print and Easy Read.

The services we can offer are: Training; Mediation/Advocacy; Payroll.

## Voluntary Director wanted

If you have any spare time then we are currently looking for a voluntary director. Although the post is voluntary we will pay reasonable expenses. We are specifically looking for someone who has experience of marketing and dealing with the media.

If you are interested in any of our services, joining our Association or becoming a voluntary director then please email: [mail@beingtheboss.co.uk](mailto:mail@beingtheboss.co.uk) or you can contact us via our Registered Office at 22 Holly Place, Moreton, Wirral, CH46 9QZ.

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2010 published 29

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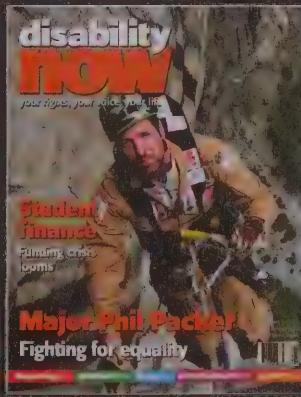
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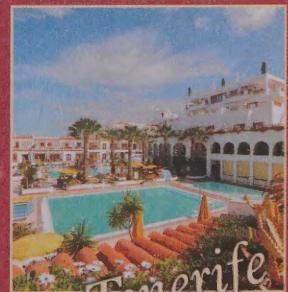
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# backlash



## The great Paralympic wobble

"Failed Paralympian" are two words which now dog **Paul Carter**. But have they made him bitter? No, he's up for a whole new challenge

**H**ello again Backlashers. That's my pet name for you all by the way. Don't be offended, it's a compliment.

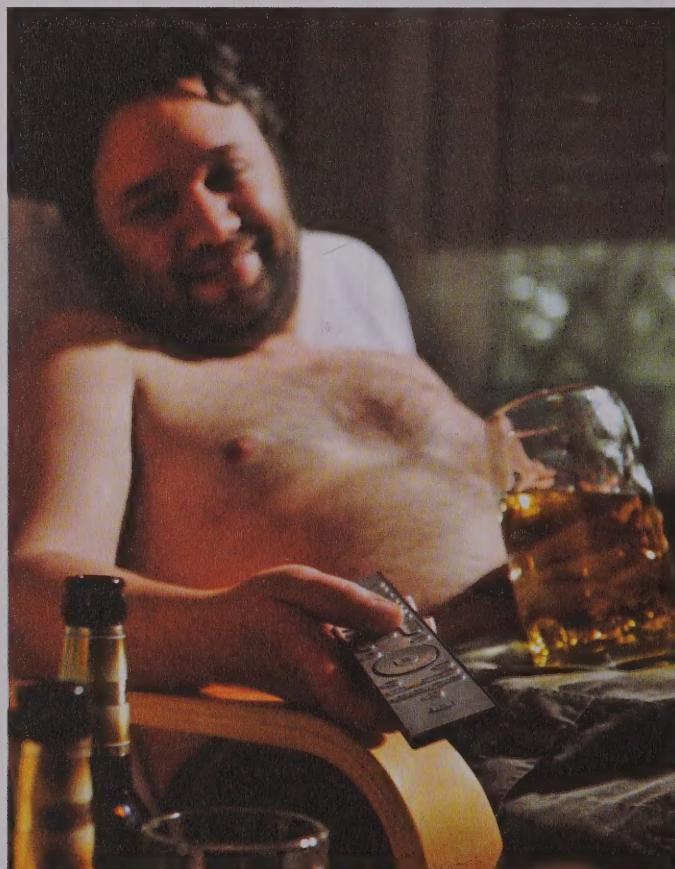
Anyway Backlashers (I quite like it, sorry), as I may have mentioned before, I often receive my fair share of (frankly bizarre) requests, invitations and offers in my *Disability Now* inbox.

In fact, over the course of my life I've been asked to take part in all forms of weird and wonderful activities. Someone asked me if I'd ever tried mouth painting the other day, which was particularly random.

However, one arrived yesterday that raised more than a smirk – the subject was "Win a Professional Football Contract". They clearly don't know me. Mind you, the club in question was Swindon Town, so maybe I did have a chance of at least making the bench.

Anyhow, after my recent brush with nearly being roped into playing Murderball, it got me thinking about my own sporting failures.

You see, but for one tired arm movement back in the halcyon days of the mid



ALEXANDER RATHS

**“They should have a proper Paralympics for people like me who are too lazy to bother training for things”**

1990s, I could have made the Paralympics. Yep, believe it or not, before I succumbed to the temptations of cheap

lager, microwave ready meals for one, and the delights of spending endless hours sat in front of pointless television, I used to swim competitively, and would have probably made the Atlanta Games had I not been disqualified for finishing my final stroke incorrectly.

It's a story I regularly bore people with in the pub, how

I was cruelly denied my sporting dreams by an over- officious jobsworth.

Looking back though, I'm actually acutely relieved, as the thought of getting out of bed at the crack of sparrow's farts in the morning to do physical exercise is now so alien to me that I almost cannot comprehend why anyone would choose to do it.

The more I think about it, the more I reckon they should have a proper Paralympics for people like me who are too lazy to bother training for things that are far too much effort, like running or pushing a wheelchair about. Sample events off the top of my head – how fast you can put on and take off an artificial leg? The 30m wobble while carrying a hot kettle, with penalties for any spillage. That kind of thing. It would give the great unfit like me a chance to taste success rather than the daily dose of abject failure and underachievement. We could call it the Idlelympics. In fact, nobody steal it, I'm off to patent it now. Sky will take it on. I'm sure I'm onto a winner.

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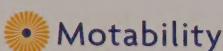
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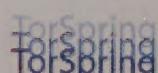


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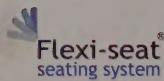
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